

Music Lessons: Exploring the Role and Meaning of Music Among Community-Dwelling
Older Adults with Dementia

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Dedication

To Poppy – for sparking my interest in dementia.

I wish you could be here now.

Abstract

An aging population and increasing rates of dementia point to the need for alternative strategies to allow individuals to age in place. The purpose of this multiple case study is to explore, from an insider's perspective, the role and meaning of music in the lives of individuals with dementia who are aging in place. The following three questions guide this exploration: *What does music mean to someone with dementia and if/how has this changed, over time? How does music influence the health and wellbeing of individuals with dementia? How is music integrated into the day-to-day lives of individuals with dementia aging in place?*

Critical qualitative research was conducted through semi-structured interviews, observations, and videos. All three participants were in the early stages of dementia, living in the community (not in an institution), residing in Ontario, using music in their lives in a routine capacity, and not enrolled in music therapy. The partners of each of the participants were also included in the data collection process. The qualitative data was analyzed following a 10-step process that integrated the textual, auditory, and visual data. Analysis revealed that music plays a beneficial, yet complicated, role in these individuals' lives. Analysis highlighted 'connection' as the central theme of the study with the various 'connectors' - self, partner, music and the study itself - as subthemes. Connection to self is discussed through present moment awareness, accessing memories, and self-expression. Connection to partner is explained in light of self-connection and spending time together. The connection to music acknowledges the self and partner as well as the need to keep things "ordinary". Lastly, connection to the research is a methodological finding that speaks to the transformative nature of qualitative research.

Findings from each sub-theme are described using examples from the data and discussed in relation to the literature.

This study provides insight into the growing body of interdisciplinary literature dedicated to dementia, music, aging in place, and contemplative practices, as well as makes suggestions for future areas of research.*

* Keywords: Community-dwelling, connection, dementia, music, qualitative

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Chapter 1 Introduction

In Canada, seniors represent the fastest growing age group. In 2011, an estimated 5 million Canadians were aged 65 years or older, a number that is expected to double in the next 25 years (Statistics Canada, 2011). A significant consequence of population aging in Canada is the increasing rates of elderly-targeted illnesses and diseases (Alzheimer's Association, 2014). Of these illnesses, dementia prevalence has been significantly affected, appearing at a record high (Alzheimer's Association, 2014). Dementia is defined by the World Health Organization (WHO) (2015) as "a syndrome in which there is deterioration in memory, thinking, behavior, and the ability to perform everyday activities". Dementia is a degenerative, irreversible illness that presently has no cure (World Health Organization, 2015). Older adults represent the population most affected by this illness; in 2011, 14.9% of Canadians 65 and older were living with dementia, a number that is projected to significantly increase over the next 15 years (Alzheimer Society of Canada, 2012), making dementia one of the most significant public health issues of the 21st century (Alzheimer's Association, 2014).

Older adults with dementia reside in long-term care homes, assisted living, hospitals, and at home in the community. The majority (60-70%) of people with dementia live at home in the community (Alzheimer's Association, 2012), and transition only in the later stages of the illness to an institution. There are varying factors that lead families to this decision of institutionalization, most prominently the increasing severity of cognitive impairment, a diagnosis of Alzheimer's disease and subsequent worsening of symptoms, increased dependency for daily activities, and increasing behavioral and psychological symptoms (Curtin, 2010). The desire to remain at home where things are familiar and navigation is easier is strong among older adults with dementia - a person's home reflects their identity, achievements, independence, competence, and self-esteem - factors which are important to maintaining quality of life, health and happiness for people with dementia (Gould & Basta, 2013).

Caring for a person with dementia takes a physical and psychological toll: up to 75% of caregivers will develop a psychological illness such as depressive or anxiety disorders, 15-32% will experience depression, and they are at an increased risk for

obesity and a weakened immune response (WHO, 2015). A common result of these factors is caregiver burnout; more than half (55%) of caregivers felt worried or anxious as a result of their caregiving responsibilities (Statistics Canada, 2012). As such, there is an established need for accessible, cost-effective strategies that support family caregivers in caring for their loved ones at home, while maintaining their own health and well-being (Hanser, Butterfield-Whitcomb, Kawata, & Collins, 2011).

Pharmacology has been the traditional approach to treating dementia and a common strategy for enabling older adults to remain at home. Drug treatments however, have been largely unsuccessful and ineffective in alleviating many of the main symptoms of dementia, such as anger, agitation, wandering, psychosis, and/or apathy (Nair, Browne, Marley, & Heim, 2013). In response to the poor success of drug therapies, non-pharmacological interventions, such as art therapy, massage, reminiscence and music therapy, are emerging as new and important approaches to dementia care and treatment. Non-pharmacological interventions aim to address the underlying needs such as lack of sleep, comfort, nutrition, and socialization that are causing the inappropriate behaviours instead of masking them with medication, something that has the potential to enhance the quality of care and improve communication between the caregiver and person with dementia (Cohen-Mansfield, 2001). Of the many alternative therapies available today, according to the literature, music therapy is one of the interventions that individuals with dementia most often respond to (Foster, 2009). Potentially, some have argued, because the parts of the brain required for the processing of musical information remain intact regardless of a dementia diagnosis (Davidson & Fedele, 2011; Foster, 2009). This means it is possible that musical perception, sensibility, emotion, and memory can survive even after other forms of memory have disappeared (Foster, 2009).

1.1 Importance of the Study

Given population aging, the rising rates of dementia, the chronic nature of the illness that enables older adults to live many years after diagnosis, and the desire of individuals, families and the government to keep people with dementia in their home environment for as long as possible, it is crucial for alternative therapy strategies to be created and utilized with this population. Research is needed to understand the role that

music plays in the lives of individuals with dementia who are aging in place in order to simultaneously defer institutionalization as long as possible while increasing the quality of life for older adults with dementia and their caregivers.

1.2 Purpose and Questions

To date, much of the research on music and dementia has focused on: a) institutionalized settings (e.g., long-term care facilities) and, b) structured professional music therapy interventions. Much less is known about music among community-dwelling older adults. The purpose of this case study was to explore, from an insider's perspective, the role and meaning of music in the lives of individuals with dementia aging in place. The following three questions guided this exploration:

1. What does music mean to someone with dementia and if/how has this changed, over time? *What was the role that music played in their life before the onset of dementia as compared to the present?*
2. How does music influence the health and wellbeing of individuals with dementia? *Does music affect individual factors such as identity? Memory? Selfhood? Does music affect social factors such as engagement? Relationships?*
3. How is music integrated into the day-to-day lives of individuals with dementia aging in place? *Is music played from a personal device or projected aloud throughout the house? Is music used at certain times of the day or to accompany certain activities? Is music used as part of a routine or spontaneously?*

1.3 Organization of the Thesis

In this first chapter I introduce the topic area – music among community-dwelling older adults with dementia – contextualize the study within the fields of community health and dementia, and provide the research purpose and questions that guide this study. In *Chapter 2 Scoping Review* I present my published review of the literature along with three additional areas – selfhood and dementia, caregiving, music and health – that emerged as important over the course of the study.

In *Chapter 3 Theoretical Framework and Paradigm* I outline the theoretical framework for the study, an adapted version of The Psychosocial Model of Music in

Dementia, and describe the interpretivist paradigm that guides the study. Additionally, I explain how this study aligns within critical qualitative health research.

In *Chapter 4 Methodology and Methods* I provide a detailed description of the case study methodology and interview, observation and video methods employed. I also describe the recruitment process and selected participants, study sites, and ten-step data analysis procedure. A quality assessment of qualitative research is reported, followed by an explanation of the role of the researcher. This chapter concludes with the identification of the ethical considerations and the limitations of the study.

In *Chapter 5 Findings and Discussion* I present the results of the data analysis. Data, including quotes, field notes, and photographs/video captures are used to illustrate the overall thematic finding of connection. Sub-themes of connection to self, partner, music, and the research and researcher are also explored. Each of these sub-themes is summarized in a discussion that reflects the key theoretical influences used for interpretation.

The final chapter, *Chapter 6 Conclusion*, summarizes the main findings of the study. As well as highlights the contributions to knowledge in the area of dementia and music including various methodological contributions. To conclude the chapter I suggest future directions for research in this area.

Chapter 2 Scoping Review

As an alternative to a literature review, a scoping review was conducted for this study. The scoping review has been published in the academic journal *Dementia* (see Appendix A). As the study progressed additional areas of literature became relevant: selfhood and dementia, caregiving, and music and health. The following is a review of these areas, which complement the literature covered in the scoping review.

2.1 Selfhood and Dementia

A key component of maintaining a high quality of life and care for individuals with dementia is the acknowledgement and understanding of their sense of self. The seminal work of Kitwood (1997) describes how personhood is directly linked to identifying one's self-worth and dignity, and how with a diagnosis of dementia individuals are often treated and cared for in ways that depersonalize and infantilize. Ultimately this leads to a loss of personhood that is often only associated with the neuropathology alone and does not account for the self and agency that remains (Kontos & Naglie, 2007). Pia Kontos' work builds on Kitwood's notion of personhood and discusses the idea of embodied selfhood as an expression of ourselves based on a notion of agency that "resides below the threshold of cognition, and facilitates meaningful engagement with the world" (Kontos, 2014, p.112). Kontos goes further to discuss how even persons with severe dementia continue to express themselves through their bodies (P. C. Kontos, 2005, 2012; P. C. Kontos & Naglie, 2007; Mitchell, Dupuis, & Kontos, 2013).

A study on elder-clowning (a red-nosed clown who specializes in working with older adults through music, dance, and humor) with 23 long-term care residents with dementia showed that residents would initiate as well as respond to verbal and embodied engagement (P. Kontos, Miller, Mitchell, & Stirling-Twist, 2015). Participants opened their eyes, began smiling, stomped their feet along to the beat the clowns played on their ukuleles, and joined in on playful teasing between the clowns and residents (P. Kontos et al., 2015). Embodied engagement and accessing the insiders' perspective (the individual with dementia) is a strategy to account for this selfhood. For example, a study by Post (2013) described many cases of the enduring self in dementia, one of which discussed a

conversation between the researcher and a nursing home resident, Mr. G, with dementia. The researcher was engaging in direct conversation with Mr. G asking him questions about his past, and although he could not verbally respond he instead gave the researcher an important physical object from his childhood as an alternate form of communication and thus, a representation of his enduring selfhood (Post, 2013). In dementia care, selfhood represents a newly reemerging perspective that provides a unique opportunity to identify new insights and previously unconsidered ways of understanding.

2.2 Caregiving

Caring for a person with dementia takes a physical and psychological toll: up to 75% will develop a psychological illness such as depressive or anxiety disorders, 15-32% will experience depression, and they are at an increased risk for obesity and a weakened immune response (WHO, 2015). As the demands of the caregiving role increase, caregivers often are forced to reduce or quit employment and limit social activity, making them vulnerable to social isolation and adding financial stress (Brodaty & Luscombe, 1998; Vitaliano et al., 2005; WHO, 2015). A common result of these factors is caregiver burnout; more than half (55%) of caregivers felt worried or anxious as a result of their caregiving responsibilities (Statistics Canada, 2012). These various negative effects of caregiving are well documented in the health literature while the benefits of caregiving are seldom discussed.

Research shows that positive aspects of caregiving are most commonly found in the caring itself or the dynamic of the relationship between caregiver and care recipient (Lloyd, Patterson, & Muers, 2016). Some caregivers feel companionship, fulfillment, enjoyment, love, and empathy through the act of caring (Boerner, Schulz, & Horowitz, 2004; Shim, Barroso, & Davis, 2012). In particular to dementia, an important precursor to finding joy in caring was the acceptance of the changes in their shared life with their loved one (Lloyd et al., 2016; Shim et al., 2012). The dynamic of the care relationship can also affect the caregiver benefit. Spousal relationships that are central to the individuals' lives are more meaningful as a caregiver (Boerner et al., 2004; Fauth et al., 2012). Spousal caregivers often treat caring as an extension of their marital relationship and not as an additional burden (Cheng, Mak, Lau, Ng, & Lam, 2016; Lloyd et al., 2016).

Although they may still experience burden, spouses, in particular, wives, conceptualize caring as a natural part of their role as a life partner. Specifically with dementia, some caregivers feel emotionally closer to their care recipient after the diagnosis and the newly increased amount of interaction and time spent together (Fauth et al., 2012). With both the burden that some caregivers experience as well as the benefits, there is an established need for accessible, cost-effective strategies that support family caregivers in caring for their loved ones at home, while maintaining their own health and well-being (Hanser et al., 2011).

2.3 Music and Health

Music therapy is well documented in the health literature over a wide range of health issues and illnesses. However, viewing music and health outside of a therapeutic lens is less prevalent. Specifically examining older adult's health and the connection to music, the majority of findings are institutionally-based and conceptualize music as an intervention that allows older adults to remain well (Fraser et al., 2015). For example, a scoping review in the area of arts and aging, found that 58.3% of included studies were intervention based and only 28.9% of studies were exploring current personal artistic and creative activities (Fraser et al., 2015). Removing this medical lens and discussing engagement with music as an everyday common activity for older adults is shown to have positive outcomes (Laukka, 2007). Specifically, in a study surveying 500 community-dwelling older adults in Sweden found that 64% of participants listened to music once or several times a day, and the reasons for listening included pleasure, mood regulation, relaxation, feeling of belonging, and connection to their identity (Laukka, 2007). The informal listening and making of music improves cognitive (stimulation, memory), social (engagement), and emotional (joy, relaxation, stress relief) wellbeing leading to self-perceived successful aging for older adults (Creech, Hallam, McQueen, & Varvarigou, 2013; Laukka, 2007; Sole, Mercadal-Brotons, Galati, & De Castro, 2014; White, 2016).

2.4 Scoping Review Results

The results of the scoping review pointed to several gaps in knowledge in the area of music and dementia: (a) there is a lack of diverse methodology and methods used in this area, most of which are quantitatively focused; (b) the majority of music

interventions are structured and professional-led, such as music therapy; and (c) the perspectives of the individual's with dementia are largely missing from the literature. This study aimed to address aspects of each of these gaps by utilizing a qualitative methodology, exploring music as it is used in the daily lives of individuals not in a professional therapeutic setting, and by interviewing the individuals with dementia themselves.

Chapter 3 Theoretical Framework and Paradigm

The purpose of this qualitative study was to explore, from an insider's perspective, the role and meaning of music in the lives of individuals with dementia aging in place. An interpretivist perspective shaped this understanding.

3.1 Theoretical Framework

The Psychosocial Model of Music in Dementia (McDermott et al., 2014) guided the construction of this study. The model proposed by McDermott et al. (2014) emerged out of a lack of frameworks in the area of music and dementia, and from a lack of understanding about how and why music is an effective therapy. This model highlights the diversity of the meanings of music in the lives of persons with dementia and consists of three main categories of factors that are influenced by music: *here and now*, *who you are*, and *connectedness* (See Appendix B). *Here and now* refers to the immediacy of the responses to musical stimuli experienced by individuals with dementia, including emotions, enjoyment, and self-expression. In the adapted version of the model I labeled this category "Meaning" (See Figure 1). *Who you are* is explained as being predominantly influenced by fixed factors such as previous life events and personality traits, as well as personal psychology and personal identity. In the adapted model I labeled this category "Selfhood". The *connectedness* category describes how musical experiences often result in experiences of emotional connectedness with other people, sharing of experiences, and developing relationships, also affected by social psychology and the care home environment (McDermott et al., 2014). In the adapted version of the model I labeled this category "Relationships". I chose to rename these labels because these were the main themes from the literature on music, dementia, and aging in place, and better suited my study.

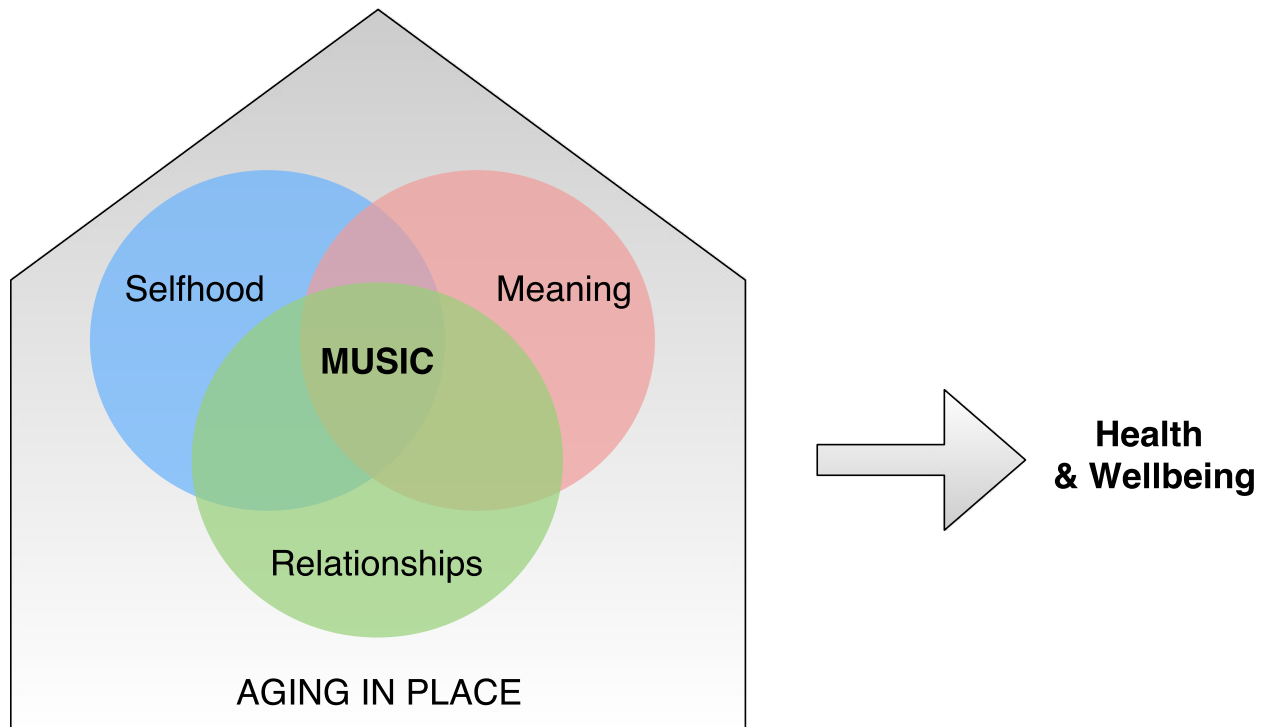


Figure 1. Modified version of the Psychosocial Model of Music in Dementia (McDermott et al., 2014).

According to McDermott et al. (2014) these categories can be conceptualized holistically where a successful here and now intervention allows each person with dementia to be who they are which in turn leads to meaningful connectedness with other people and their environment (McDermott et al., 2014). I chose to connect all three categories through the shared concept of music, as the literature in this area highlights how music is seen to affect meaning, selfhood, and relationships of individuals with dementia. I also chose to encompass all three of these categories into the environment in which they operate, which, for this study, is the home. Connecting these factors to the overall health and wellbeing of individuals is important, as they are the outcomes described in the literature in the area of music and dementia. Health researchers conceptualize wellbeing as a meaningful state of life (Andrews, Gillett, & Voros, 2016). Thus, how a person derives meaning from their everyday activities is central to their wellbeing (Sixsmith & Gibson, 2007). Positive wellbeing (i.e. happiness and life satisfaction) comes from being involved in activities that are personally meaningful and valued, while negative wellbeing results from the inability to participate in these

activities (Sixsmith & Gibson, 2007). In summary, this model provides a framework for music as a meaningful activity that can contribute to overall health and wellbeing. The modified Psychosocial Model of Music in Dementia aided in theoretically framing my study as it has the key elements supported by previous research in the area of music, dementia, and aging in place.

3.2 Paradigm and Approach

Guba and Lincoln (1994) define paradigm as the basic belief system that guides researchers in their fundamental way of knowing, relative to their own experience, in their subjectivist view of the world, and in their choice of method. The paradigm I worked within was interpretivism, also known as social constructivism. Generally, interpretivism raises questions about meaning and one's being and about what the world must be like in order for one to know and be in it (Schwandt, 1996). In order to truly know one's environment, interpretivism suggests the use of one's own, and others, lived experiences as a tool (Schwandt, 1996). Specifically, interpretivism proposes that reality is socially constructed; it is always conditioned by one's experiences and culture (Guba & Lincoln, 2005). Interpretivism assumes that human beings construct meaning as they engage with the world, and then make sense of this interaction based on the historical and social perspective that we have bestowed upon us by our culture (Creswell, 2003). The nature of knowledge under interpretivism is subjective and interactive, which drives the research in this area to reflect understanding and interpretation (Guba & Lincoln, 2005). Interpretivists aim to be clear about the fact that they are constructing reality on the basis of their interpretations of the data provided by the participants in the study (Patton, 2002). I agree with others who argue that all research involves some degree of interpretation, and the paradigm of interpretivism simply makes this explicit and brings interpretation to the forefront of the research.

Interpretivism was an appropriate guide for my research not only because it is my personal worldview but it also allowed me to get to the core of what I was asking through my research questions. Interested in the role that music plays in the lives of individuals with dementia who are aging in place in their own homes and communities, I wanted to explore what music *means* to these participants; experience and meaning are the

fundamentals of interpretivism (Guba & Lincoln, 2005; Schwandt, 1996). My study, under the instruction of interpretivism did not only allow me to interpret my participants' subjective views of the world by providing time for me to interact and build relationships with them, but allowed me to be explicit about the interpretations that I made from my participants' data. This interpretation occurred at many stages of my study, from interpreting the setting of the interviews and what meaning these environments had on the individuals with dementia, to their body language and mannerisms while listening to or making music and being interviewed, to interpreting their responses to the interview questions and attempting to give meaning in the form of themes to these answers.

Ontology and epistemology question what one believes about the nature of reality, and how do we know what we know, respectively. As an interpretivist I believe in relativism, meaning that multiple interpretations account for a single phenomenon, and that knowledge is transactional, in that it is socially constructed by both participants and the researcher, whom are interlocked and active in the research process (Gastaldo, 2015). In this study I embodied the ontological and epistemological beliefs of interpretivism by explicitly accounting for all of the participants' diverse perspectives and my own interpretations of these views in the final write-up of the study. The research methodology and methods that follow are from my interpretivist paradigm.

3.3 Qualitative Research

Quality qualitative research is framed by various special characteristics: it is interpretive, experiential, situational, personalistic, well triangulated, and well informed (Stake, 2010). A qualitative research approach is one in which the researcher makes knowledge claims based primarily on interpretive perspectives (Creswell, 2003). Qualitative research often takes place in a natural setting, uses multiple open-ended and interactive methods of data collection, focuses on a single concept or phenomenon, collaborates with participants, and makes interpretations of the data with the primary intent of developing themes (Creswell, 2003). Qualitative inquiry is defined by emergent design, in that it is open to adapt when situations or understanding changes (Patton, 2002).

Qualitative research was an appropriate design for my study because it explores the hows and whys that exist in society, it searches for meaning and description behind culture, phenomena, and/or individual experience, dependent upon which qualitative methodology is employed. Furthermore, the population of individuals with dementia who are aging in place is a group that has rarely been studied.

Critical qualitative research seeks not just to study and understand society, but also to critique and change it (Patton, 2002). Typical critical health studies ask questions such as: what are the health challenges facing individuals now and in the future, and how are they experienced? (Andrews, Gillett & Voros, 2016). A critical qualitative research lens questions and takes into account: received knowledge, underlying assumptions, social forces and interests at play, models of thinking, power relationships, and people and issues that are marginalised in mainstream policy (Andrews, Gillett & Voros, 2016; Eakin, 2015). The nature of my study originated from the critique that the perspectives of people with dementia are often unconsidered in dementia research. My study attempted to acknowledge and understand the person behind the illness. This study fit within this realm of critical research by: a) questioning the assumption that alongside a diagnosis of dementia there is a loss of selfhood and, b) attempting to explore the perspectives of a seldom studied population – individuals with dementia who are aging in place.

Chapter 4 Methodology and Methods

I utilized a multiple case study methodology for this research. Case study is an “empirical inquiry that investigates a contemporary phenomenon in-depth and within its real-life context” (Yin, 2009, p. 18). In light of my study purpose and research questions – to explore the role and meaning of music in the lives of individuals with dementia aging in place – I explored the meaning and use of music in the lives of those with dementia. This exploration was best suited to a case study methodology because the research questions sought to explain how or why some social phenomenon worked, and the more the questions require an in-depth description, the more relevant the case study method is (Yin, 2009). In particular to my study, the research questions were seeking to explain how music affects those with dementia aging in place, and because the questions were exploring concepts like meaning and selfhood, the exploration required more than a simple answer or observation, but an in-depth look into the lives of these individuals.

The following characteristics, based on the work by Yin (2009) and Patton (2002), guided this research:

- Ask good questions and interpret the answers
- Be a good listener
- Be able to identify nonverbal messages
- Be adaptive and flexible
- Be sensitive to how the setting can affect what is said
- Be aware of changes in the interviewer-interviewee relationship
- Be unbiased by preconceived notions

I embodied these qualities through the use of a holistic multiple case study research design. A case study can be thought of as a close-up, it is an example of micro research that involves studies conducted on the scale of local neighborhoods and individuals (Stake, 2010). A multiple case study, uses more than a single case, but remains an example of micro research (Stake, 2010). The benefits of a multiple case study research design is that the evidence tends to be more compelling making the overall study more robust (Yin, 2009). The holistic portion of the multiple case study was significant as it guided the design in the direction of exclusively exploring the global

nature of music and dementia in the community with a single-unit of analysis (Yin, 2009). The unit of analysis for this case study was each of the couples, the individual with dementia and their partner/caregiver.

A case is defined by Miles and Huberman (1994) as a “phenomenon of some sort occurring in a bounded context”; these boundaries are often set by time, place, and activity (Creswell, 1998). In this study the case was the individual with dementia and their partner, bounded by time: time since the diagnosis, place: their home in Southern Ontario, and activity: the experience of music. The case was further defined by a set of case study questions that reflected the researcher’s line of inquiry and kept the investigator on track as data collection proceeded (Yin, 2003). The research questions guided the case study questions in focusing the field notes during observation and the interview line of inquiry. The case study questions were also a reminder of what I set out answer and guided my thinking in much of the analysis stage. The case study questions for this study were as follows:

1. What is the musical life story of the individual with dementia?
2. What is the meaning of music to the individual with dementia?
3. What are the practical uses of music in the day-to-day life of the individual with dementia?
4. What is the influence that music has on the individual with dementia’s health and wellbeing?

I selected 3 cases where music currently played a role in the lives of individuals with dementia aging in place, in an unstructured and non-therapeutic way. Selected participants were individuals with dementia and their partners who were using music in their lives daily; either purposefully listening, dancing, or singing along to music.

The process for conducting a multiple case study that is exploratory is as follows: develop a theory, select cases and design data collection protocol, conduct first, second, and third case study, write individual case reports for each case, draw cross conclusions between cases, modify the theory, develop implications, and write a final cross-case report (Patton, 2002; Yin, 2009). A brief account of the procedures I used in my case study can be viewed in Table 1 and a detailed account under Data Collection and Data Analysis.

Table 1

Procedures for Conducting a Case Study Modified from Creswell (2012).

Case Study Procedures	My Study
The problem relates to understanding an event, activity, process, or one or more individuals.	Understanding music in the lives of individuals with dementia aging in place
Identify the type of “case”, such as intrinsic, instrumental, or collective.	Multiple case study
Receive approval from institutional review board.	Received approval from the Brock University Research Ethics Board
Locate a research site using purposeful sampling procedures.	Homes of each of the participants
Identify how many cases you plan to study.	3 cases
Identify a gatekeeper to provide access.	Various Alzheimer Societies in Southern Ontario
Collect extensive data using multiple forms of data collection.	In-depth interviews, observations, and videos
Read through data to develop an overall understanding of it.	First read through of transcriptions, field notes, and videos
Describe the cases in detail and establish a context for it. Develop themes about the case. Conduct a within-case analysis.	Multiple readings of the data and began coding, categorizing, and developing themes within individual cases. Compiled master documents for each case.
Follow the within-case analysis with a cross-case analysis.	Multiple readings of the within case analyses and developed overarching themes between individual cases.
Write report, taking into consideration description, analysis and interpretation. Include your biases. Generalize to other cases.	Wrote final thesis report that included findings, discussion, and future implications, ensuring I was explicit about my positionality.

4.1 Participants

4.1.1 Recruitment. I recruited participants using established connections with three local Alzheimer Societies in Southern Ontario. I originally met with the Director of Programs who then began advertising my study in their various programs, along with running an advertisement of my study in their newsletter (see Appendices C, D and K for recruitment materials). I was eventually successful with recruitment four months later; in the meantime I explored other connections. I had received a grant from another Alzheimer Society and thus had connections at this site. I reached out to their Director of

Operations who circulated my recruitment materials and advertised my study on their social media sites. From these efforts I was successful in recruiting another participant (and their partner). Lastly, I was put in contact with another Alzheimer Society branch that directly put me in contact with my last participant (and their partner). Overall, recruitment proved to be a challenging process with a total duration of 10 months.

As no definitive number of cases is necessary or outlined in case study methodology texts (Yin, 2009), I studied three cases in-depth. Rolling recruitment was utilized, in that I began data collection upon recruiting the first participant and during this time was recruiting others. Three cases was appropriate for this study for various reasons: it was a Masters thesis and therefore was confined by time and resources, recruitment of willing individuals with dementia was challenging, and the case study methodology with interviews, observation, and videos yielded a wealth of data to analyze. Qualitative research is not concerned about sample size but instead the value of the cases studied and the observational and analytical capabilities of the researcher (Creswell, 2012; Patton, 2002). As such I believe that studying three cases provided sufficient and in-depth data.

4.1.2 Selection. The eligibility criteria for selection of participants were as follows: they had to be experiencing dementia, they could be living alone or with others, living in the community and not in an institution, residing in Southern Ontario, using music in their lives in a routine capacity, and not enrolled in any formal music therapy. See Table 2 for a list of the criteria along with the rationale for each.

Table 2

Participant Eligibility Criteria and Rationale for Participant Selection.

Criteria	Rationale
Experiencing dementia	A key aspect of the research is being able to capture participant perspective, and therefore they needed to be able to conceptualize and verbally communicate with the researcher (this is often not possible in later stages of dementia). However, because stages of dementia are often subjective I opened the criteria from “early stages” to experiencing dementia.
Living alone or with others	This did not affect the study results.

Living in the community and not in an institution	The population of interest was older adults who are aging in place (i.e. not institutionalized). Participants could be living in their own homes/apartments, homes/apartments of family members or friends, assisted living, or senior's residences. Not in long-term care facilities, nursing homes, or hospitals.
Located in Southern Ontario	Feasibility and time and resource constraints.
Using music in their lives in a routine capacity	A key focus of the research was exploring the medium of music, and for this to be effective music needed to be used purposefully in their lives and not just by coincidence (i.e. background music in the car, at the mall etc.).
Not enrolled in any formal music therapy	A key component of the study was music in the daily lives of these individuals, and not music as a therapy with structure and guidelines.

4.2 Study Sites

The observation, interviews, and video recording occurred at the participants' homes located in Southern Ontario. The reasons for conducting the data collection in the participants' homes, in addition to the fact that the home environment was a key aspect of the study as we were interested in individuals who are aging in place, were that: individuals with dementia tend to be more comfortable in environments that are familiar to them and, the nature of the study aimed to explore the use of music in the day-to-day lives of individuals with dementia.

4.3 Data Collection

I collected data over a 7-month period, utilizing a rolling recruitment strategy, where I began with one participant (and their partner) and during this time of meeting with this individual I continued recruiting for my next participant. I visited each of the three couples three times over the course of three to five weeks (depending on the participant's schedule), for a total of nine visits. Each visit had approximately one to two weeks between the next visit, my intention was one week but sometimes, because of conflicting schedules, a two-week period was granted. I visited my participants

frequently as dementia is a degenerative illness affecting memory, thus I wanted to avoid reestablishing rapport upon every entrance into the participants' homes and did not want to spend too much time collecting data. The frequent visits also provided an opportunity to remind participants to be using the video camera when I was not present during the week between visits. The initial visit was time to do introductions, read and complete the letter of consent, and begin building rapport. The two following visits were used to conduct interviews on the topic area and sometimes, depending on participant preference, film their engagement with music. Each visit lasted anywhere from thirty minutes to three hours.

The original intention was to only collect data from the individual's with dementia themselves, as they are the "insiders" on their own experience with music, and their perspectives are largely missing from the literature. However, upon meeting each of these participants and discovering that their sole caregivers were their spouses along with, for most of their lives, their musical partners, not collecting data from their partner's perspective appeared to be limiting. Additionally, each of their spouses wanted to be present during the interview process and were highly engaged in the conversation and the video taping of their engagement with music. This realization led me to have their partner's complete an informed consent letter and collect and include their data in the study.

4.3.1 Interviews. The case study's unique strength is its ability to deal with a wide variety of evidence, from documents and artifacts to interviews, and observations (Yin, 2009). I utilized semi-structured interviews, observations, and artifacts in the form of videos for this case study. Qualitative interviewing begins with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit (Patton, 2002). A semi-structured interview is conducted over a short period of time (one hour), has an open-ended, conversational nature, but is structured in that it follows a certain set of questions derived from the case study protocol (Yin, 2009).

Communication can be challenging for persons with dementia. The most common communication issues experienced by these individuals are: problems finding the right words, lack of logic in speech, repetition of ideas, decreased attention span, and forgetting of events, names, and/or faces (de Vries, 2013). In preparing for these

interviews I read literature on how to effectively communicate with individuals with dementia and what to typically expect in these situations. I addressed these difficulties through a number of strategies outlined by Wilson et al. (2012): slowed speech rate, simple sentences, asked only one question at a time, eliminated distractions, established and maintained eye contact, repeated messages using the same wording, and avoided interrupting the person. The literature also discusses that when possible, closed-ended questions should be utilized with this population. As this was not possible for the exploratory nature of this study open-ended questions were utilized. However, evidence from Small et al. (2003) illustrates that when open-ended questions demonstrate respect and are based on person-centred topics, such as the meaning and role of music in their life, individuals with dementia have been shown to have positive and meaningful responses.

It is important to note that although I understand the value in preparing for data collection with this population, through the reading of literature on research with individuals with dementia and working with vulnerable populations, not all of this rang true. I am hesitant to further sensitize us to this population as “vulnerable”. I had conversations with my participants that were very similar to conversations I would have with other, younger research participants. There were times when their memory did affect their answering of the interview questions but I was always able to come up with alternative ways to get to a similar answer, or to continue on and come back to it at a later time. Nevertheless, preparation is an important aspect of the pre-data collection phase, however keeping in mind that there may be a disconnect between the label of “vulnerable” and the actual experience is important.

Non-verbal communication accounts for facial expressions, eye contact, posture, appearance, gestures, and body contact (Jootun & McGhee, 2011). For individuals with dementia non-verbal communication can offer another avenue that can be equally, if not more effective than expressing themselves in words. As suggested by the literature (Maxim & Bryan, 2006; Small et al., 2003) I communicated non-verbally with participants through: sitting face to face, established eye contact, used gestures to help explain questions, used a calm tone of voice, gave the individual time to respond, and moved slowly. The video collection for this study was also rationalized by the importance

of non-verbal communication and being able to capture these expressions and movement on film.

I conducted two semi-structured interviews, ranging from one to three hours each, with each of the three couples. An important aspect of these interviews was that they elicit the views and opinions of the individuals with dementia who are aging in place (Creswell, 2003), while simultaneously satisfying the researcher's line of inquiry (Yin, 2009). Open-ended questions were used to satisfy these criteria, as this type of question enables the researcher to understand and capture the point of view of the interviewee without forcibly directing the topic of conversation (see Appendix E for the Interview Guide) (Patton, 2002). When necessary, I also used probes to deepen the response to a question, redirect the answering, and/or give cues to the interviewee about the level of response that was desired (Patton, 2002).

The strengths of interviews as a method of data collection for this case study were that they focused directly on the topic of music and dementia, and they were insightful, as they provided inferences and explanations of the experience and meaning of music in their lives (Yin, 2009). All semi-structured interviews were audio recorded for later stages of transcription and analysis.

4.3.2 Observation. Direct observation occurred simultaneous to interviews; participants were observed on three separate occasions. The strength of observation as a data collection method is that it covers events in real time and can elaborate on context (Yin, 2009). Understanding context is essential to a holistic perspective, and provides the opportunity to see things that may routinely escape awareness of the people in the setting because it is something they see or deal with on a daily basis (Patton, 2002). Observation also provides a platform to learn things that people might be unwilling to talk about in an interview (Patton, 2002).

Field notes were used to supplement the audio recordings of interviews. They were recorded in a notebook with a structured manner, immediately following the interviews (Creswell, 2003). Often times simple field notes or memos were written on the interview guide as the interview was conducted. Field notes contained basics such as the date, where it took place, and who was present. Along with more detailed observations of the physical setting, social environment (what interactions took place, what was said, any

direct quotations), nonverbal communication, and any other elements I believed were worth noting, including my own feelings, reactions and reflections on the experience (Patton, 2002). In particular to this case, notes taken during observation followed the guide found in Appendix G and concentrated on artifacts in the home that were related to music (i.e. stereos, posters, instruments), observable emotion during the talking about, listening or making of music (i.e. tears, smiles, frowns), personal identifiers related to music (i.e. tattoos, blisters, clothing), physical movement during the listening or making of music (i.e. dancing, tapping, clapping), along with notes on the home environment and specifics on how and where music was utilized. The observation guide also accounted for notes on other aspects of the setting and participants outside of the ones listed above.

4.3.3 Videos. I collected visual data in the form of videos. Videos can be used for note taking at a later date, and for recording certain processes or activities (Pink, 2007). With the participants' consent I videotaped them listening to or making music in their home environment. An additional option that I offered to participants was to keep the video camera with them during the time between interviews. This option offered an opportunity to capture more visual data and during a time when the participants may feel more comfortable, without the researcher present. The participants were given a handout with a list of examples of moments that they could capture with the camera, as well as simple instructions on when and how to do this (see Appendix H). An instruction card was attached to each video camera with simple steps on how to power the camera on and off, and how to begin and stop recording. They were encouraged to use the video camera whenever the opportunity presented itself over the data collection period. (Explicit instructions to use the video camera four to five times, each time lasting two to ten minutes, over the course of one month were on the handout). Participants could set up and use the video camera themselves, which one couple did, however, if the couple needed assistance with the video camera, I was available to film these moments for them, this occurred at the end of the allotted interview time.

The benefits of videos as a data collection tool are that they have the potential to capture detail in observations that can be missed in the moment, can capture a different, visual side of the participant that cannot be expressed in words, in addition to being a stable artifact and therefore can be reviewed repeatedly (Pink, 2007; Yin, 2009). Videos

have the potential to increase the quality of field observations and the utility of these observations to others (Patton, 2002). I selected to use videos over photographs, as one of the central topics of this research is music, which is best captured through the additional audio aspect of video (Pink, 2006).

4.4 Data Analysis

Qualitative data analysis is an ongoing, iterative process that begins with the construction of the research questions and continues until the final write up of the study (Creswell, 2012). The basic principles of case study analysis outlined by Yin (2009) are to ensure that the researcher is attending to all of the evidence, addressing all major interpretations and the most significant aspects of the study, including those findings that rival one another, and remembering to use one's prior expert knowledge. At its simplest, case study analysis includes a detailed description of the individuals and setting, followed by reviewing and analyzing of the data for themes (Creswell, 2003). The interpretation of case study data is considered micro interpretation as it gives meaning based on what an individual person can experience, as compared to a large group or body of individuals (Stake, 2010).

Content analysis refers to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings called patterns and themes (Patton, 2002). As part of this first phase of data analysis I reviewed the interview transcripts upon completion of the interviews in order to improve or adjust the line of questioning for the following interviews. I conducted inductive content analysis for this study. Inductive analysis is based on the notion that findings emerge through the analysts' interactions with the data, and in the direction from the details to the more general codes and themes (Creswell, 2012; Patton, 2002). These findings are discovered beginning through a process of memoing and open coding, reading through the transcripts and field notes for possible thoughts, hunches, categories, and patterns (Creswell, 2012; Patton, 2002). These codes can be derived through indigenous concepts, key phrases or terms that are special to the people in the setting studied, or sensitizing concepts, things the researcher has taken from the literature and knows going into the fieldwork will be important (Patton, 2002). Coding requires

multiple readings of the data to develop the coding categories and then to begin coding in a systematic way (Patton, 2002). After reading through, and coding the data multiple times, the researcher can begin looking for convergence, or redundancy to combine codes into larger themes (Creswell, 2012). It can often be helpful at this stage to use colour coding to distinguish different categories or themes. The overall goal is to reduce the list of codes to get five to seven themes; similar codes aggregated together to form a major idea (Creswell, 2012). Once I had identified the major themes and no new information could be added to the list or to the detail for existing themes, I had reached saturation (Creswell, 2012).

The above descriptive phase of analysis laid the foundation for the interpretative phase (Patton, 2002). Interpretation should aim to confirm what we know that is supported by the data, disprove misconceptions, and illuminate important things that we didn't know but should know (Patton, 2002). The overall analysis process is meant to organize and elucidate the story of the data while not forcing it in a certain direction (Patton, 2002). Thus the researcher needs to be explicit about their interpretations of the data. Once themes have been created, interpretation of the meaning of these themes involved analytic induction, the use of theories to bring understanding and draw conclusions from the data (Patton, 2002).

Combining Creswell (2003) and Stake (2006) steps for data analysis in qualitative research along with Heath, Hindmarsh & Luff (2010) steps for video analysis my analysis for all study data (audio recordings, transcripts, field notes, and videos) was as follows:

- **Step 1: Edit the interview guide.** Prior to the last interview, I listened to the first audio file while looking at my overall research questions and interview guide. I wrote down any additional questions, further prompts, or missed questions for the follow-up interview.
- **Step 2: Organize and prepare the data for analysis.** Upon completion of data collection with each participant I typed up field-notes, gathered all video, picture, and audio files into digital participant specific folders, and sent audio files to be transcribed.
- **Step 3: Read through/view all the data.** Upon completion of all interviews and receipt of all transcripts I did a first read through and view of the data. This

allowed me to obtain a general sense of the information and reflect on its overall meaning. This involved me printing the documents, reading through the transcripts multiple times and making memos in the margins. I watched each video multiple times making time-stamped memos and thinking about where this visual data may fit into the textual.

- **Step 4: Begin coding.** After multiple read-throughs and viewings some of these memos merged or stood alone to become codes. These categories were labeled with either indigenous or sensitizing concepts/codes. This step represented an iterative process and required multiple read-throughs of the data for each case.
- **Step 5: Compiling of the data.** After coding the transcripts and watching the videos I started creating master documents for each case (see an example in Appendix L). These documents included a chart with the personal information survey data, what I considered to be important coded sections of the transcript, key field notes that related to the coded transcript, and screen captures from videos or photos that contributed to these areas. Following this I read through these documents and started making notes on greater themes between the cases.
- **Step 6: Create and meet with an analysis team.** At this point, to gain perspective and clarification, I assembled an analysis team that consisted of two other Master's level graduate students in health sciences and my supervisor. I provided this team with the three master documents for each couple, removing the codes I had assigned. I wanted the team to have an unbiased perspective on the data, although I recognize these were not the full transcripts and I had tailored what was available to them. The team had one week with the documents and then we met for two hours to discuss their interpretations of the data and what they thought was most important.
- **Step 7: Conduct cross-case analysis.** Taking the team's perspective into consideration I reexamined the three master documents and the codes I had found and started making some preliminary thematic notes on these areas. As well as a similarities and differences chart between the three cases (see Appendix M), and a diagram outlining the progression of the disease and the effects it has on the individual and the partner relationship (see Appendix O).

- **Step 8: Advance how the themes are represented in the qualitative narrative.**

I narrowed down my categories into six main themes (identity and change over time, connection, complication and challenges, humor, music as a contemplative practice, transformative nature of qualitative research) and began pulling specific examples of these themes from the transcripts into separate documents according to each theme. As some of these themes were in areas that I had not read about before (i.e. music as a contemplative practice, transformative nature of qualitative research, etc.) I performed literature searches in these areas.

- **Step 9: Write multiple storylines of the data.** With feedback and instruction from my supervisor I wrote three storylines (three different perspectives on the whole story that could be told from the data). The thesis of each story was as follows: 1) There is value in the use of music for and with individuals with dementia however, this is complicated. 2) The health and wellbeing of persons with dementia is influenced by music through selfhood, meaning, and relationships (as outlined in the theoretical framework). 3) In all three cases music acted as a catalyst for connection, both for self-connection in the individual with dementia and connection to their partner (see Appendix N for an example). Upon completion and review of each of the storylines, stories one and two were found to restrict the data. In particular, storyline two which was framed according to the categories in the theoretical framework did not provide the most comprehensive view. Attempting to fit the data into the framework's predetermined areas, instead of letting the data guide the conceptualization, was shown to be limiting. For example, organizing the data into the adapted theoretical model's categories of meaning, selfhood, and relationships left out important aspects of the methodological findings as well as deemphasized the idea of connection that was shown to be a significant finding.

- **Step 10: Make an interpretation or derive meaning from the data.** This step involved my personal interpretation and assertions of the main themes. I decided to expand on a combination of storyline one and three with the main theme of connection, while acknowledging the complicated aspects of music, as this told the truest and most thorough depiction of the data. Storyline two, outlined by the

theoretical framework, influenced the conceptualization of the final storyline through the use of some of the sensitizing concepts (selfhood, meaning, and relationships). This step also involved future research implications, questions, and gaps.

4.5 Quality Assessment

Tracey (2010) suggests eight criteria for achieving quality in qualitative research, they are: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence. These criteria differ from the traditional reliability, validity, and generalizability that are often used in quantitative research and then modified to fit qualitative studies. Instead, these eight criteria are tailored specifically for qualitative research. See Table 3 modified from Tracey (2010) for a description of each of these criteria, and how I employed them.

Table 3

Tracey's (2010) Quality in Qualitative Research Criteria and the Plan to Enhance the Quality of this Study.

Quality Criteria	Meaning	Employing them in my Study
Worthy Topic	The topic of research is relevant, timely, and interesting (challenges well accepted ideas and questions assumptions).	The topic of music and dementia is increasingly relevant with the growing aging population and increasing incidence rate of dementia. Including the perspective of people with dementia challenges the idea of a loss of self for these individuals.
Rich Rigor	The study uses sufficient, abundant, appropriate, and complex theoretical constructs, data and time in the field, data collection and analysis processes.	I was guided by a theoretical framework that was derived from a modified version of the Psychosocial Model of Music in Dementia (McDermott et al., 2014). I spent 7 months with multiple visits to each of the participants. I used

		multiple data collection methods in the form of interviews, observations, and videos.
Sincerity	The study is characterized by self-reflexivity about subjective values, and biases, and the researcher is transparent about the methods and challenges.	I was explicit about the role I had in the research at all stages (see Role of the Researcher section). There were challenges and limitations to this study and I was transparent about these (see Limitations section).
Credibility	The research is marked by thick description, concrete detail, triangulation (the use of multiple methods to study a single issue (Patton, 2002)), and multivocality (addressing participants' different perspectives especially those that diverge from the majority).	Thick description and concrete detail was provided through multiple transcriptions and field notes. This study employed triangulation through the use of in-depth interviews, observation, and video recordings. Additionally, accepting and encouraging the perspectives of each individual interviewed addressed multivocality.
Resonance	The research influences, affects, or moves particular readers through naturalistic generalizations (feeling of personal knowing and experience).	This research intended to impact readers (i.e., other researchers, individuals with dementia, and their loved ones), from a place of similar experience. This was achieved through detailed description of these cases, the use of quotations when applicable, and sharing of the key findings.
Significant Contribution	The research makes a significant contribution conceptually/theoretically, practically, or heuristically.	This research could be useful for other individuals caring for loved ones with dementia at home. This research also made a contribution by addressing the gap in knowledge regarding the perspectives

		of individuals with dementia who are aging in place.
Ethical	The research considers procedural, situational, relational, and exiting ethics.	See section titled Ethical Considerations.
Meaningful Coherence	The study achieves what it purports to be about, uses methods and procedures that fit its stated goals and meaningfully interconnects literature.	This study was best suited to an interpretivist approach and case study methodology, and benefitted from the use of interviews, observation, and videos.

4.6 Role as the Researcher

Reflexivity, the constant self-conscious, scrutiny of the self as researcher and of the research process, is necessary in order to make explicit personal assumptions that are brought to the research process and data analysis. In order to reflect on my a priori assumptions and to consider how these assumptions as well as my position (e.g., young, educated, woman) influenced my interaction with research participants and impacted data analysis, I kept a reflexive journal throughout the process. As a qualitative researcher I positioned myself within the study and was conscious of how my values, beliefs, and assumptions affected the line of inquiry. I systematically reflected on my role within the study through my reflexive journal.

I approached the study from the perspective of someone who is significantly younger, yet has an appreciation and curiosity for old age and the aging process. I am someone who has been volunteering with the Room 217 Foundation and has been involved behind the scenes on a sing-along project for individuals with dementia and therefore has had access to some of the preliminary data of the effects and success of this project, which has significantly affected my knowledge in this area. I am also someone who has observed and been personally affected by dementia. With two grandparents with dementia, one who has passed, and one who is now in the early stages of the illness, I recognized that my personal experience affected how I collected, interpreted and felt throughout this process.

By acknowledging my creative presence (coined by Joan Eakin), in this study I not only recognized my positionality (e.g. prejudices, judgments, assumptions, thoughts,

vested interests) but put it to use. I achieved this by asking myself: why might it matter that I am a student/woman/someone who has personally seen the effects of dementia? In what way will this affect me as a researcher? Does it cloud certain issues? Preclude certain questions I might ask? Blind me to certain things? Limit my conceptual reach? (Eakin, 2015). Upon asking myself these questions I was aware and documented my answers so that I could potentially have my awareness point to important aspects or illuminate other parts of my point of inquiry, and so I could be explicit when writing up the final research report (Eakin, 2015).

Reflecting between interviews was also helpful. Critically thinking about the quality and quantity of information from the first interview and what could improve in the following interviews was an informative process and led to changes and additions to the interview guide. This awareness of my own positionality allowed me to keep a clear distinction between the participant's voice and my own analytic interpretation (Eakin, 2015).

4.7 Ethical Considerations

Research with humans requires a variety of considerations to ensure that ethical guidelines are met and participants are respected. These include informed consent, confidentiality, and protection from harm, especially when dealing with a vulnerable population who has a limited capacity for self-determination, such as individuals with dementia.

4.7.1 Informed consent. Determining whether the participants have the capacity to provide consent was the first step in this process. There were three opportunities for this assessment to take place. The first time was through the recruitment process and the individuals at the Alzheimer Society locations acting as gatekeepers to these individuals. If the representatives from these organizations felt that the individuals were capable of participating this was one moment of assurance. The next opportunity was the first call between the participant and myself to discuss the research purpose, study description and details, in addition to how and where they heard about the study. This call provided me with an opportunity to assess the potential participant's ability to participate through the answering of some basic questions. The last opportunity was the first meeting between

the researcher and potential participant, along with their partner, before the signing of the consent form. This meeting provided another opportunity for me to assess the capacity of the individual with dementia, as well as the partner, face-to-face. If I believed they would be appropriate participants, the first thing I did when approaching them was to provide detailed information regarding the nature and purpose of the study (Creswell, 2003).

Once this information had been fully disclosed, each research participant was in a clear agreement with myself, of their participation, and they gave written informed consent (see Appendix F), understanding that they had the right to withdraw at any point throughout the study (Creswell, 2003; Yin, 2009). As the choice to include the partners as participants occurred in field, the researcher did confirm with the research ethics board that a modification to the protocol was not needed. Partners also read and signed an informed consent letter prior to their participation. Informed consent refers to the expressed willingness of those being researched to participate based upon full disclosure of the aims, methods, and intended uses of the research results (David & Sutton, 2011). If the participant requested, I would read the informed consent letter along with additional information about the study out loud to them to ensure that they were completely aware and understanding of the aims and purpose of their involvement. Ongoing verbal consent was utilized throughout the study to ensure that the participants remained interested in participating and did not feel that they were being taken advantage of in any way (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). I also ensured, as part of the informed consent that the participants were completely aware and comfortable with the interviews taking place in their place of residence, along with being videotaped during their engagement with music.

4.7.2 Confidentiality. While the participants completed an informed consent letter and during the interview process itself, they were able to clarify any questions or concerns that arose, which were then immediately addressed by the researcher (Creswell, 2003). I was prepared that if, during the interviews, information that I considered to be private or possibly damaging was shared, this information would either be removed or disguised with the use of pseudonyms. In particular to video and audio ethics there were times when people outside of the participants were videotaped (friends from choir) or interrupted during the audio recording (family and friends) and in these instances this

data was not used. Confidentiality involves the non-disclosure of information to parties other than the research team and protection of personal information (David & Sutton, 2011). For this study, pseudonyms were used to protect participant's personal information, however, full anonymity could not be guaranteed with this study, as video data was collected, this was stated in a disclaimer on the informed consent letter. Additionally, as part of the informed consent letter, participants had the opportunity to opt out of the video component of the study, while still remaining in the other components (interviews and observation) but again, this did not occur.

4.7.3 Protection. Protection of study participants from any harm over the duration of the study is always a central ethical concern in research, and is amplified when working with a vulnerable population like individuals with dementia. This population is considered vulnerable due to their mental state and neurological impairments (Creswell, 2003). Special precautions were taken to make sure that participants were aware and clear at all times of what the study purpose was, such as preparation for ongoing verbal consent, and clarifications on questions or the purpose whenever needed (Yin, 2009). Participants were made aware that while listening to music and being videotaped they were not expected to perform or exert themselves in any way, and if at any time they were upset or concerned, the observation or interview process could be terminated. An additional method of protection that the researcher employed was the ability to reschedule the interview if the participant was having a bad day. These same precautions also ensured that participants were comfortable throughout the entirety of the study.

4.8 Limitations

Case study, although effective for exploring in-depth the experiences of individuals, has limitations. Focusing on data collection, and specific to interviews, the dynamics of the relationship between interviewer and interviewee can be problematic, if a power relationship is felt, or contrary when a participant begins to feel overly comfortable, sometimes distorted responses because of anxiety, emotions or for self-serving reasons can occur (Patton, 2002). I addressed this power dynamic through building rapport during my multiple entrances into the study site, and my presence (i.e. casual attire, posture, etc.). Additionally, a limitation that affects both interviews and

observation is my presence during the seven-month study. This may have had an effect on how the participants behaved or felt, construing the results, known as the interviewer effect (David & Sutton, 2011). I acknowledge that the study design and co-production of data means that my participants may have ‘performed’ for me during our time spent together, as in life, it is common to feel the need to impress when meeting a new person for the first time. However, my response to the interviewer effect and relationship dynamic, was to spend time with participants over multiple visits and to comfort the participants as much as possible during the interview process. The repeated visits provided more opportunity for building rapport and less pressure on the second and third visits after having previously met one another.

An additional limitation that affects observation is the limited scope of what the observer can take in (Patton, 2002). It was impossible to observe every possible thing that was occurring in the setting, but I did my best to observe a wide range of activity, this was helped by multiple occurrences of observation for each case. Videos are also limited by their credibility, in that they can be edited without permission (Patton, 2002). However, with only myself having had access to these videos, ensuring that they were not tampered with was not an issue.

For my study I interviewed and observed three cases, which yielded an in-depth view into the role of music and dementia. These cases were unique in that all participants lived in the community with their partners, all of who were their primary informal caregivers. Each couple also had extensive experience with music, most of which they had experienced together as a partnership. As such, findings are limited to these unique cases and this particular context, and cannot be generalized to, for example, individuals who live alone, or to those who have participated in a lifelong meaningful activity that is not music.

4.9 Conclusion

The purpose of this study was to explore, from an insider’s perspective, the role and meaning of music in the lives of individuals with dementia aging in place. A modification of the Psychosocial Model of Dementia in Music and the interpretivist paradigm outlined the framework of this study. The characteristics of qualitative research

directed the case study methodology and the data collection methods, along with the data analysis process. This study embodied the 8 criteria for quality in qualitative research, and the stated ethical considerations.

Chapter 5 Findings and Discussion

The aim of this study was to explore from an insider's perspective, the role and meaning of music in the lives of individuals with dementia who are aging in place. The findings reveal that music plays a beneficial, yet complicated role in these individuals' lives. Analysis highlighted 'connection' as the central theme of the study with the various 'connectors' - self, partner, music and the study itself - as subthemes (see Figure 2). In this chapter I begin with an introduction to the participants, an explanation of the major theme of connection, followed by a discussion of each of the sub-themes. Connection to self is discussed through present moment awareness, accessing memories, and self-expression. Connection to partner is explained in light of self-connection and spending time together. The connection to music acknowledges the self and partner as well as the need to keep things "ordinary". Lastly, connection to the research is a methodological finding that speaks to the transformative nature of qualitative research. Findings from each sub-theme are described using examples from the data and discussed in relation to the literature.

5.1 The Participants

In order to contextualize the use of music in their daily lives, I conducted all interviews with the participants in their homes. All of the participants used music in an informal way and lived with their partners, who were also their sole, informal caregivers. The following are pieces of their musical stories.

George has always loved to dance – solo, partner, or in a group. He began dancing when he was 14 years old in the United Kingdom. George continued dancing, even when he was deployed in Africa in the army. When George met Beth, his wife of 68 years, they began dancing as a couple and have continued to do so throughout their lives together. Due to the dementia diagnosis, they recently stopped dancing at the legion, church, and other events but continue to dance in the kitchen.

Tim discovered his skill and love for singing late in his life. Tim's family roots are Welsh and he often speaks to the music engrained in this culture. He began learning to play piano when he was a young boy and continued with tuba and trombone in high school. There was a period of time in his adult life when he no longer engaged with

music, until he met his current wife Jill. Jill and Tim began singing in their church choir 15 years ago and joined a local competitive choir 5 years ago. They are still active members in both choirs today.

Phil has spent most of his life playing a selection of instruments in a variety of drum cores. Music has always been Phil's favourite hobby; he's played contra in multiple drum cores – creating one on his own – and continues to appreciate music through listening and watching DVD's of some of his favourite performances. When Phil isn't sharing his lived experience for a local Alzheimer Society, his days are spent with his wife, Susan, sorting sports cards and listening and reminiscing to music from the past.

Table 4

Participant information.

Participant	George	Tim	Phil
Gender	Male	Male	Male
Age	94	77	65
Ethnicity	British	Welsh	Canadian
Length of time in home	24 years	22 years	7 years
Date of dementia diagnosis	2008	2012	2013
Medication related to dementia	Yes	No	Yes
Participation in alternative therapies	No	No	No
Partner name	Beth	Jill	Susan
Partner gender	Female	Female	Female
Length of relationship	68 years	20 years	N/A
Musical connection	Dancing partner	Choral singing partner	Drum core partner

5.2 Connection

“Connect (transitive verb): to join (two or more things) together” (Merriam-Webster, 2017); “connection (noun): the act of connecting” (Merriam-Webster, 2017). For individuals with dementia, connection – to self, others, and aspects of life – becomes increasingly difficult as the disease progresses (Gouveia, 2010). Wayman (2011) describes individuals with dementia as a jigsaw puzzle, pieces of which the dementia progressively removes, leaving random pieces with which one is left to connect (Olson, 2014). Music can act as a catalyst for this connection. Familiar music can aid in the preservation of self and evoke memories and associations that offer an opportunity for

intra and interpersonal connection (Foster, 2009). In all three cases for this study, music acted as a catalyst for connection: self-connection within the individual with dementia, connection to their partner, connection to the music, and connection to the research and researcher.

5.2.1 Connection to self. Music was observed as a catalyst for self-connection through the production of present moment awareness, memories, and self-expression. Individuals with dementia spend a significant amount of their time in jumbled and confusing thoughts. Therefore, having organized thoughts, and enjoying the present moment through music, is significant to allowing these individuals an opportunity to reconnect to themselves. Engaging with music (listening, dancing, singing) offered organization of thoughts for individuals with dementia and the ability to be in the present moment. Music acted as an anchor to the present moment that allowed participants moments of self-awareness and thoughtfulness. After engaging with music participants' thoughts appeared more clear and focused, allowing them to further comment on factors such as their musical performance or their struggle with dementia. For example, after practicing a choral hymn with his partner, Tim turned to me and said, "you can see I'm having difficulty" referring to losing his spot in the music and needing help from his partner to stay on track. Similarly, speaking to the clarity in his thoughts Tim explained, "Yeah, I feel good inside then and after [singing in the choir] okay? And you know, a lot of these things just keep rolling around in your head..." and "it eases the mind and away you go you know?" Phil was able to organize his thoughts and subsequently his sports card collection when music was playing in the background, "Well, I do a lot of stuff with music as far as my collections and things like that [Right] because if I have a TV on I probably wouldn't be halfway near done what I do with the music."

The organization of thoughts also allowed the purposeful access of music associated memories. Participants were able to access musical memories after engaging with music through listening, dancing, or singing. The ability to recall memories from the past connected participants to their selfhood and made them feel proud, as this is something that with a diagnosis of dementia has become increasingly difficult to achieve. After recalling a past memory on video Phil exclaimed, "wow! I like it when I can

remember things like that”. Additionally, George who was experiencing many memory issues due to dementia was able to recall vivid details of a memory after listening and dancing to one of his favourite songs:

You remember you were at a dance and this guy didn’t know the music but the woman behind him did [Yeah] so she asked him, so she asked him to put it on [Yeah] okay, *Blanket on the Ground* and then you guys danced to it? Okay, nice, we’ve got it and everybody was clapping oh that’s awesome. That’s great, you guys were good yeah, everyone thought you were the teachers. {Laughter} Yeah, that’s awesome.

Tim speaks to the connection of music and memory:

Music has that ability to, to bring you to, to a memory [Um hmm] that, that and an emotion and it brings you right back to that emotion [Um hmm] and whatever it was [Um hmm, um hmm] and uplifted, uplifted by music, sometimes depressed by music {Laughter} but not very often, if it’s very sad you know, but [Yeah, yeah] I wouldn’t say depressed but it just, it makes you feel different emotions, sadness and that sort of stuff.

Music can trigger memories for Phil unlike anything else:

Interviewer: We were talking about before how you struggle maybe with memory issues in other parts of life but with music and your listening to it you can recall things like that [Yeah] that you probably would never have been able to without it.

Phil: Right, right, but I couldn’t remember who came to see me on a Sunday [Right], last Sunday.

Additionally, music connected participants to themselves through their bodily expressions. This expression took many forms: hand gestures, mimicking how they would hold and play an instrument, dancing steps to a song, or singing along to music. Expressing their self through movement was a reminder that a “self” still existed, despite a diagnosis of dementia. Although expressing ourselves through our bodies is not the only way we show our inner “selves”, for individuals with dementia it is often one of the lasting ways they can communicate their selfhood. For example, George who no longer recognized the faces of some of his family members was still able to remember the steps

to dances he would perform with his wife throughout their life (see Image 1 – video screen capture). Similarly, while listening to music Phil was seen to move his upper body mimicking that of a conductor from his experience in drum core (see Image 2 – video screen capture). There were many examples of this type of movement in the video data.



Image 1: George and Beth dancing in their kitchen.

I cue up *Blanket on the Ground*, a song they told me used to be their favourite to dance to at public events, on my phone so that it plays aloud in the kitchen. The song reminds me of Patsy Cline, its old time country with a female vocalist who's coaxing her husband to that "spot down by the river, where our sweet love first began". Once George and Beth recognize the song, this takes about 30 seconds, as they are a little shocked about the phone technology, they embrace and begin moving together to the beat of the music. Beth places one of her hands on George's shoulder and the other in his hand. George's hands follow, on her waist and in her outstretched hand. With his hands in place he stands tall and moves, the two of them completely in sync, in what appears to be, effortlessly, around the kitchen holding his wife. The steps they take appear to be completely natural; in this moment time has not affected their ability to move in step together. They make eye contact the whole time and Beth's smile never leaves her face, it's as if I am not even there.



Image 2: Phil listening to drum core music and mimicking a conductor's movements while sorting his sports cards.

This footage is from Phil's self-videotaping. The camera is placed on his tabletop where he sits to sort his sports card collection. We have a close up view of Phil (only his upper half) and can see stacks of cards and binders on bookshelves in the background. The instrumental music – a string orchestra – is playing quite loudly and Phil appears to be completely “in the zone”. He is inserting cards into a clear file protector and nodding his head along to the music. There is a lull in the music before a new instrument chimes in. In this moment, Phil, without skipping a beat, moves his arm in an upward sweeping motion as if conducting the orchestra himself. As the music continues, so to does Phil, returning to his sports cards.

The benefits that music has on self-connection for individuals with dementia were clear. However, it must not be considered a panacea solving all problems. Memory is the primary cognitive faculty that is affected with a diagnosis of dementia. As a society that values cognitive capacity, we often associate this loss of memory with a simultaneous loss of self. While data shows participants maintain some sense of self, they are nevertheless dealing with jumbled thoughts and hard to access memories that make it more difficult to connect to and feel like themselves. Jill, Tim's partner, describes the time when Tim was first starting to show signs of dementia:

...there were just things that were happening you know, like it's, it wasn't so much forgetfulness although yes, there was forgetful like you have short term memory things [Um hmm, um hmm] but it was more getting things mixed up you know, that sort of stuff getting things mixed up [Okay] and then we started to notice when we were away in Florida that, that January, February whatever that, that Tim would have a harder time finding his, his way around like you know, like a new place that he didn't know you know? [Okay, okay] Instead of turning left

he would turn right you know, [Um hmm] which never really used to happen you know, like he was pretty good at figuring out where he was but [Um hmm] these were signs to me that something was really going on strangely.

Reflecting after my first interview with Phil and Susan in which Phil had a difficult time accessing memories and remembering some personal information I wrote:

I was shocked with his memory recall issues – it threw me off a bit and required me to act more on my feet to allow him to access certain memories – I think that because he looks so young that I didn’t think he would have those difficulties, but he was really struggling with remembering things.

5.2.1.1 Discussion. In the biomedical literature the dominant representation of dementia is as a devastating disease (Henderson, 2002). Often the most debilitating and demeaning aspects of a case are discussed and the tragedy of a diagnosis is emphasized. Of course it would be misleading to ignore the losses that are experienced by individuals with dementia and those closest to them: loss of shared memories, routines, control, friendships, to name a few (Mitchell et al., 2013). However, what my analysis revealed is that despite all of these losses there are aspects of the self that still remain and can be revealed through engagement with music. My study supports the literature on music and memory, that through engagement with music individuals with dementia can access memories that are otherwise inaccessible (Cowles et al., 2003; Hays & Minichiello, 2005; Kerer et al., 2013; Vanstone & Cuddy, 2009). Similarly, analysis revealed that a self still remains in those with dementia and through music this selfhood is revealed (P. C. Kontos, 2005, 2012; P. C. Kontos & Naglie, 2007; P. Kontos & Martin, 2013; P. Kontos et al., 2015; Mitchell et al., 2013). This study makes an additional contribution – the connection between dementia and music as a contemplative practice.

Health literature has begun to explore positive outcomes of contemplative practices. Contemplative practices aid in “developing capacities for deep concentration and quieting the mind in the midst of the action and distraction that fills everyday life” they are a “reminder to connect to what we find most meaningful” (The Center for Contemplative Mind in Society, n.d.). Music, however, as a contemplative practice benefitting health, is largely missing from this research. Unless music is linked to

meditation (Sarath, 2015; Vidyarthi & Riecke, 2014) or is used in an educational setting (Power, 2013; Shippee, 2010; Westerlund & Väkevä, 2011), and even then, there is limited research available. My findings suggest that music offers organization of thoughts and acts as an anchor to the present moment for individuals with dementia. It is through this clarity that music facilitates intentional mind wandering to past memories (Seli, Carriere, & Smilek, 2015). This is supported by the literature that shows mindfulness meditation enhances working memory, attention, focus, and intelligence for older adults with dementia (Robertson, 2015). Having control and intention in recalling memories has positive effects on an individual with dementia – maintaining identity, strengthening relationships, expressing selfhood, and experiencing feelings of joy. This research supports the literature that emphasizes the need for contemplative practices in caring for persons with dementia, as accessing the present moment experience is critical for these individuals to manage many of their symptoms (i.e., attention deficits, memory loss, disorientation) (Person & Hanssen, 2015; Robertson, 2015). This research also goes beyond previous work to suggest the power of music as a contemplative practice for individuals with dementia. As one participant said, “there is a magic to the music”.

5.2.2 Connection to partner. Music also acted as a means to connect individuals with dementia to their partners. All participants in this study were married and their primary informal caregiver was their partner. Referring to them as a caregiver does not do justice to the dynamic of the relationship and prioritizes caregiving over other aspects of their life. Thus I am choosing to refer to them as a partner as I believe this encompasses their role more holistically. Music acts as a way to connect them through a musical partnership that coexists with their caregiver and care receiver roles.

This connection built upon the self-connection that participants experienced. It also provided an activity they could both share in. During and after engaging in music, partners reconnected through recalling memories, self-awareness, or embodiment. Partners seized this as an opportunity to connect with their loved one and share in a moment together. With dementia, finding moments to connect are rare and thus the sharing of the present moment is invaluable. Phil and Susan spend time together in their basement listening to music from their past and reminiscing on moments spent together:

And we play a lot of trivia on a, on artists, who the artist might be [Okay] you know, we also I don't know about him but I know myself I try to pick out different instruments that you might hear through the, the music. A lot of times we try and figure out what we were doing when we heard this song.

Participants' embodied selfhood was recognized by their partner and provided a moment of connection similar to those before dementia. I witnessed these moments of connection on the video data and when present during the engagement of music. After dancing with her loved one to a song from their past, Beth exclaimed, "we haven't danced like that in years!" (see Image 3 – video screen capture).



Image 3: Beth recognizes George's body movement and they engage in a dance together.

About 30 seconds into one of their favourite songs from their past Beth and George make eye contact and smile – they recognize the tune. Beth reaches for George and he responds by embracing Beth in a dancing position, hand in her hand and hand on her waist. Beth's facial expression shows her surprise as she quickly makes eye contact with me, as if to say "are you seeing this?!". It's only a moment before her eyes and smile return to George and the two of them begin box stepping around the kitchen. George leads Beth to the beat of the music; they appear to be completely comfortable in each other's arms – a familiar place. Beth's smile never leaves her face.

In all three cases music gave these dyads something to share and engage in together. The dementia diagnosis meant increased time spent together, as individuals with dementia needed help practicing, playing, and operating musical devices. This situation, while requiring significant changes in the way that music was integrated into their lives, provided an opportunity for the relationships to strengthen and grow. Analysis highlighted numerous ways the relationships had strengthened. For example, one couple spoke to the change in their relationship, which was also evident in their expressions and body language (see Image 4 – video screen capture):

I think since Tim's had more difficulty following music it's almost as, it's brought us closer together because we practice together all the time and there's this community, again I am back to when we are singing together there's just this feeling that goes between you, it's hard to describe it, it's like this string.



Image 4: Tim and Jill practice choral hymns together.

Tim and Jill are in their kitchen, sitting side by side, at a desk with a computer and file folders of their sheet music, their usual practice space. Both Tim and Jill hold their own booklet of sheet music for this particular choral hymn they are about to sing. Jill sits in front of the computer and pounds on the keys to get the instrumental music to play. The piano music begins and they both start to sing the tenor part in unison. Tim rocks in his chair and they remain very concentrated on the music, practicing hitting every note. Halfway through the song Tim loses his spot in the music and Jill leans over to help him find the right page in his booklet. They miss only a few beats before they pick it right back up. They end the piece repeating the lyric “a beautiful song”, the piano ends and Tim and Jill turn to each other, they smile and laugh.

The strength and resiliency of these relationships has developed through the struggle and challenge they've encountered post-diagnosis. Dementia, due to the nature of the disease, affects not only the individual but also those closest to them. As their partners take on a caregiving role the dynamic of the relationship changes. There is tension between holding onto the past and embracing their new circumstances. Certain activities or events they used to engage in together they cannot any longer. Partners express missing the more social aspect of their lives pre-dementia, "we've got no friends anymore" and:

I do, [miss the social aspect of drum core] I do [Um hmm] I, I really do. [Um hmm] We don't have dances anymore, [Um hmm] I love to dance [Um hmm] Phil loves to dance when he, when he's not on, unbalanced but the noise, if there's too much noise or if there's we have got to make sure there's no strobes or anything like that.

5.2.2.1 Discussion. Pia Kontos has discussed embodied selfhood in relation to dementia. Kontos discusses how persons with severe dementia continue to express themselves through their bodies (Kontos, 2005, 2012; Kontos & Naglie, 2007; Kontos & Martin, 2013; Kontos et al., 2015; Mitchell et al., 2013). She speaks specifically to the connection of music and embodied selfhood stating, "the persistence of musicality despite advanced Alzheimer's disease exemplifies the existential expressiveness of the body that I argue is a fundamental source of selfhood" (Kontos, 2014, p. 114). Research also shows that our embodied selfhood is an expression of our relationality with others and as a means for social bonding or familiar recognition to occur (Kontos, 2014; Mitchell et al., 2013). Combining embodied selfhood and present moment awareness perpetuates relational presence allowing for the reciprocal nature of engagement (Kontos et al., 2015).

My findings support the literature on embodied selfhood in those with dementia and further suggest that the participant's embodiment is recognized by and beneficial to their partner, providing a moment of relational presence and thus, connection for the couple. The moments of connection and the increased amount of time the couple now spends together post-diagnosis was shown to strengthen their relationship. This finding is

contrary to what is portrayed in much of the caregiver literature that discusses burnout and depression. Evidence for both connection to the self and others challenge the idea that with a diagnosis of dementia there is only loss.

5.2.3 Connection to music. The connection to music, for both participants and their partners, occurred as a consequence of the connection to self and others that it fostered. Individuals with dementia were connected to music because it provided opportunities of feeling like their self, connecting to their loved one, and the continued, enjoyable presence it played in their life. For example, when a participant was asked if they rely on music in any way he replied, “If you are not feeling too good and you go and you lie down what do you do, you turn on the music don’t you [Um hmm] yeah, so there is that aspect of it” and “it basically it helps up here [pointing to his head] and calms you, yeah, calms yourself down.” Partners connected to music for similar reasons, familiar recognition of their loved one, sharing in a moment together, and the consistent, pleasurable role it played in their life. When partners were asked about what music did for them that other things could not, or if they relied on music in any way, they explained:

Well, at the present time it, it lifts me up [Yeah] yeah, [Yeah] because I can you know, sometimes you get like a little bit of depression [Um hmm] because of certain things [Um hmm] and, and I’ll come on in the kitchen still and put the music on and it lifts my mood up yeah.

If I think of a world without music or, or a, a life without music I can’t even imagine that, I’d have to have music in my life [Um hmm]. I think when I was younger it was much more music oriented because you know, you are into songs, pop songs and so on and, and yeah, I think I rely on music as kind of comfort, as a, as a, a companion almost you know, in your life [Um hmm] you know, it’s something there and, I hope you know, to always have it, as I said I can’t imagine a world without music, [Um hmm] my world without music yeah.

The connection to music fueled the want, and arguably need, of both the participant and partner to hold onto this piece of their life that still felt “normal” amidst so much change. For example, when talking about their choir involvement Tim’s partner

stated, “I would like him to continue as long as he can so I am trying to you know, play that sort of balancing act”. Both participants and partners expressed the importance of music in their life and when asked what life would be like without music they replied, “How would that be, I think we would probably end up, or I would probably end up getting it somehow or another.”

Interviewer: Can you imagine your life without music?

Phil: No.

Interviewer: And why not? {Long pause}

Phil: Right there, right [pointing at his partner, Susan].

Interviewer: Yeah, and because, and because you think music brought you together right?

Phil: Yeah.

Music also proved to be a challenge for the participants. Participants began to, or had already forgotten how to play their instrument, practice choral singing, read music, and/or use devices for listening to music. In the medical literature the term apraxia is used to identify similar behavior to “forgetting how to”, meaning the loss of the ability to independently initiate purposeful movement, this could be a potential explanation for what was experienced here (Chandra, Issac, & Abbas, 2015). They were also losing control over their thoughts and memories, thus losing the ability to feel like themselves. For example Phil had to leave drum core because:

...we left while Phil was having problems physically [Okay] so we had to, he had to kind of give it up [Okay] and he, he went back a couple of times but he found he just couldn't do it and then we tried to go back to the ensemble [Okay] and he was going to play baritone but he, he just couldn't figure it out, he got confused.

Partners also felt the struggle of dementia through the constant need to find new ways to integrate music into their lives, the challenges of moving back and forth from a musical partner to a caregiver role, and anxieties about the ever-changing complications they would face on a daily basis. Partners wanted to keep things consistent for themselves and their loved one but were struggling to do so. For example, Jill explained:

The choir as much as I love it it's becoming more a bit stressful for me because I am worrying about him instead of doing my own practicing [Um hmm] so, but I just, I would like him to continue as long as he can [Um hmm] so I am trying to you know, play that [Um hmm] sort of balancing act and it's [Um hmm] getting a little difficult (Overlaps). [Um hmm] But I, I can't blame that on the music per se although maybe I can in a way, [Um hmm] maybe it's just my personality and my [Um hmm] desire to you know, make it work.

All of these factors led to a change in the relationship to music for both the individual and their partner. Where they once turned to music for enjoyment and an escape from everyday life they are now finding themselves increasingly frustrated with not being able to perform, practice, or listen how they used to, "It does frustrate you because [Yeah] you know, you, you always have been able to do something and then all of a sudden whoops {Laughing} [Yeah] it ain't working." Instead of an escape, in many ways music is a reminder of all of the change and loss that dementia has caused.

5.2.3.1 Discussion. Overwhelmingly the literature on music and dementia is positive. Music has been shown to enhance feelings of wellbeing, increase social interactions, heighten one's sense of empowerment and control (Sixsmith & Gibson, 2007). My findings also support these positive aspects, however, analysis revealed that music is not a panacea. At times music can increase the frustration of both the person with dementia and their partner, as they struggle with not being able to use/perform music how they used to and are searching for new ways to keep it in their lives. Personalizing (meaning customizing or selecting to meet individual needs, specifications or preferences based on life experiences) support strategies is key, it is important to find what is meaningful to them and explore ways to keep this in their life. Someone who has never listened to music may not suddenly appreciate and be calmed by it after a diagnosis of dementia. Similarly the type of music is important for personalization, as is the implementation strategy. There is a significant amount of information recommending the use of iPods for persons with dementia (Rossato-Bennett et al., 2014, <http://musicandmemory.org>) however, all of my participants listened to music aloud in their homes and not from an individual playing device. These devices individualize the music

experience, separating the person from their partner and potentially losing the opportunity to connect. Beyond framing music as a therapeutic intervention to address behavior, I further suggest offering it as an activity that enriches the lives of persons with dementia and their partners.

5.2.4 Connection to the research and researcher. The connection that participants experienced to the research process was found to be a key methodological finding in this study. The qualitative research process, nature of the interview method, subject matter, and the involvement of the researcher were transformative. The positive change was seen in enhancing the partner relationship, learning new things, and recognizing the importance of music in their life with dementia. It is clear that the connection to self, partner, and music occurred for these participants outside of the research interviews. When participants were asked to describe the importance of music, how it makes them feel, and what it does for them that other things can't, they answered with descriptions of moments that showed connection to their self, partner, and music. Their involvement in this study simply provided an opportunity for these couples to talk about the role and meaning of music to them, and in this process of talking there was meaning. The interviewing process prompted persons with dementia, along with their partners, to engage in meaningful conversation where their voices were both heard and valued. For example, Beth, the partner of George, a man with dementia who uses a speaker to talk stated, "he doesn't do much talking at all. No, he's done more talking here than in a long time." Another example of the research process positively transforming a relationship was highlighted through a statement by Tim's partner, "Just listening to each other you know, we go through life just so busy and, and you know, we don't talk about certain things and, and this, this has triggered that which is really, really good." At the end of data collection, when participants were asked if they enjoyed the process they expressed that, "just sitting and talking is just great" and "we needed the company."

The subject of the interviews – music and dementia – elicited reflective moments and opportunities to learn new things. For example, one of the couples that had been married 68 years were sharing stories about their musical history that the other had not

heard, “now, now I am hearing things.” Reflecting on this moment I recorded in my field notes:

At one point (when George was recalling the story about dancing overseas) Beth mentioned that she was learning things about him, she hadn’t heard that story before, this was so rewarding for me, to hear that something new was coming up after 68 years of marriage, seems like the point of qualitative research – to get at meaning and experience that maybe we haven’t shared or thought of in this way before.

Additionally, this was the first time for some participants making the connection between music and health, thus realizing that, “as I am listening to you I, I think I should be using more, music more because you know, I, I could be using it more to relax me or make me you know when I am frustrated...” After speaking with Phil about music and health I wrote in my field notes:

He hadn’t thought about music in this way before – it had always been in his life as a hobby and something he enjoyed and was very good at but he hadn’t made the connection to his health – there was a disconnect between thinking about the benefits of music versus the role it just naturally played in his life.

The co-production and dialectic nature of qualitative research was shown to be transformative for the participants and the researcher. Field notes showed that I would often go into interviews feeling anxious and ill-prepared; however, I would leave after sharing an emotional moment with participants feeling grateful and uplifted by their willingness to be vulnerable and share their stories with me:

Even my mood was affected by the process, the stories they were sharing, and the music we were playing. I went in being anxious about the process, feeling like I didn’t have enough time to prepare because my week was so busy but as soon as I got there and had seen that she had already pulled pictures and was ready for me I was instantly calmer. As it went on I was enjoying hearing about their past, and engaging directly with George was so rewarding for me. I felt that he was feeling validated in having his voice heard and being able to do that for him was amazing.

Plus I was learning so much, about the process of doing this kind of research and also about their story.

Furthermore, engaging in this research transformed my perspective on living with dementia and what it means to age well. I have a new appreciation and understanding of the person with dementia and partner relationship and a renewed interest in working with older adults as they experience the challenges of old age. Field notes illustrate this change in perspective:

My understanding of selfhood and dementia has been enriched by being around him (referring to George) and seeing him come to life when he's talking about some of his old memories or listening to old music and having it trigger emotions or memories for him – and the fact that he can still recall all of these things when asked...Originally, going into all of this I had thought that there was a way to separate the two people and that there would be value in getting the person with dementia's perspective beyond the caregiver (which I think has shown to be true) because its written about so much. Having real experience now, it makes so much more sense why it is written about, because the relationship is so integrated – especially with my participants where the primary caregivers were spouses who had been in these relationships for 30 plus years – its not like these people separated the role of wife and caregiver, they were both of these things all of the time. It was just really evident with them today and the patience she has with him and the dynamic of that relationship and that it can be a really complicated one, but these couples are all excelling because they love each other so much – it's a beautiful thing to see.

5.2.4.1 Discussion. The transformative nature of qualitative research is seldom talked about in the health literature with the majority of its presence found in clinical therapy and counselor researcher (Nelson, Onwuegbuzie, Wines, & Frels, 2013). Qualitative researchers are hesitant to claim themselves as therapists and thus avoid making transformative or therapeutic claims. However, the explicit methodological importance in this study could not be ignored. When participants were asked about their

thoughts on the study, all commented on enjoying “the company” or that “just sitting and talking is great”. Throughout the process participants, all of whom had been married for 20 plus years, shared new experiences and learned from each other. Accessing and sharing meaning and experience in this way is the heart of qualitative research and its impact and importance cannot be quantitatively measured.

My findings build on the idea that in qualitative research the researcher is a key instrument in creating a therapeutic environment where the participants feel safe, at ease, and listened to (Nelson et al., 2013). Using my creative presence and the awareness of my positionality I was able to create this environment (Eakin, 2015). I was aware of the preconceived notions and previous experience I was bringing to the interview as well as how I could use these to my benefit. This sharing of experience and willingness to learn from my participants allowed the research to transform all involved.

My findings add to this area of research by suggesting the importance of engaging in qualitative research specifically with persons with dementia. These conversations were found to be transformative for my participants who belong to a group of individuals who are often omitted from research because of their declining cognitive function. I reaffirm what other researchers have stated about the importance of discussing methodological contributions and insights in the literature so to inform other researchers in their methodological selection and conduction (Koro-Ljungberg, Mazzei, & Ceglowski, 2013).

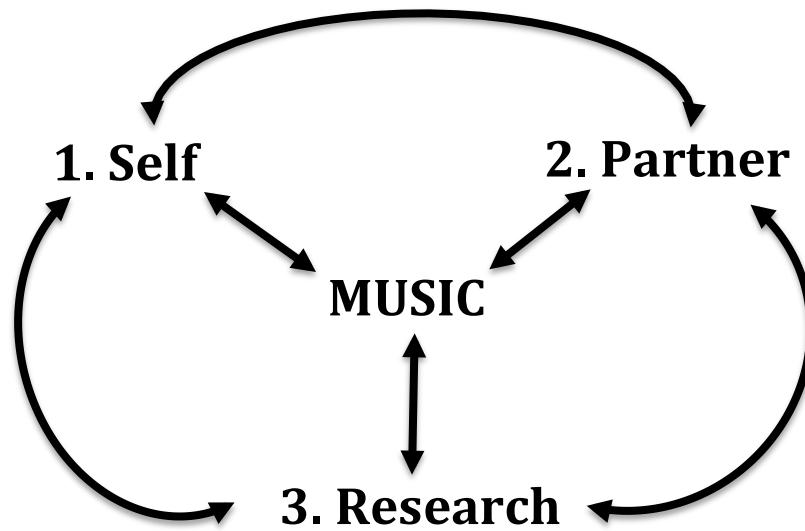


Figure 2. Thematic finding of connection: music acted as a catalyst for connection to self, partner, research/researcher, and music itself. The inner arrows radiating outwards from music show the connection to music for the self, partner and research and how once this connection is experienced, it further reinforces (double-headed arrows) the connection to music. The sub-themes are numbered in accordance with the process of connection – self-connection must occur before connection to partner, followed by connection to the research. The outer arrows represent the reinforcing of connection, for example, once the individual with dementia connects to their partner this reinforces the connection to their self.

Chapter 6 Conclusion

6.1 Overview of the Study

The purpose of this study was to explore, from an insider's perspective, the role and meaning of music in the lives of individuals with dementia aging in place. In order to explore music in the lives of these individuals I spent seven months interviewing, observing, and videotaping three individuals with dementia and their partners in Southern Ontario. The main focus of the home interviews were their musical history, the meaning and practical uses of music, as well as the influence of music on their health and wellbeing. The interview and observation guides reflected these areas. Data from these interviews consisted of audio recordings of our conversations, transcripts, my field notes, and video recordings of their engagement with music. Participants had the option to self-videotape or have me operate the camera. These options resulted in a mixture of spontaneous performances to scheduled practice. The data were analyzed following case study analysis procedures of content and interpretative analysis that allowed for integration of audio, textual and video data. The overall theme of connection along with four subthemes emerged from this process.

Connection to self. Music acted as a catalyst for self-connection through the production of present moment awareness, memories, and self-expression. Participants were able to organize, at least temporarily, their thoughts with the use of music, anchoring them to the present moment. Familiar music allowed participants with dementia to access memories that they could not recall otherwise. Additionally, individuals moved their bodies to the music in similar ways to before the diagnosis. It is important to note that despite the benefits of music, these individuals still struggled to connect with themselves as a result of the jumbled, confused thoughts and loss of memory commonly experienced with dementia. Theoretical insight into these findings was provided through the framing of music as a contemplative practice. Having control and intention in recalling memories has positive effects on an individual with dementia – maintaining identity, strengthening relationships, expressing selfhood, and experiencing feelings of joy.

Connection to partner. Music acted as a means to connect individuals with dementia to their partners through recognition of their selfhood and sharing in an activity together. Through the self-connection of the individual with dementia, partners would re-recognize their loved one and seize this moment as an opportunity to connect. Increased time spent together, as individuals with dementia needed help practicing, playing, and operating musical devices, while challenging, provided opportunity for relationship growth. Along with these beneficial moments, there were also moments of frustration and tension as partners had to adjust to their new caregiver role and the loss of social aspects of their relationship. The embodied selfhood literature theoretically grounded these shared moments of connection. The participant's embodiment was recognized by and beneficial to their partner, providing a moment of relational presence and thus, connection for the couple.

Connection to music. The connection to music, for both participants and their partners, occurred through the connection to self and others that it fostered. Additionally, music primarily had a consistent, pleasurable role in the lives of participants and their partners, and this was something that they wanted, arguably needed, to hold onto. This is complicated however, as participants lose their ability to engage in music like they used to, and partners feel the struggle to find new ways to integrate music into their lives. The research on music and dementia largely ignores these complications.

Connection to the research and researcher. The connection that participants experienced to the research process was found to be a key methodological finding in this study. The interviewing process and subject matter of music and dementia allowed participants and their partners to be engaged in direct conversation about an area they are experts on, but do not have opportunity to discuss in this way. The researcher also experienced the transformative nature of this research. Qualitative methodological texts, and in particular, clinical and counselor research, help to frame these findings. Throughout the process participants shared new experiences and learnt from each other. Accessing meaning and experience in this way is the heart of qualitative research and its impact and importance cannot be quantitatively measured.

6.2 Addressing the Research Questions

The purpose of this study was to explore, from an insider's perspective, the role and meaning of music in the lives of individuals with dementia aging in place and was guided by 3 objectives concerned with understanding the meaning of music, its influence on health and wellbeing, and its daily integration. The findings illustrate that music has always been meaningful to these individuals, as a source of enjoyment and an area they have acquired skills and talent in. Music has also been a meaningful 'connector' throughout their life, to larger social groups in the past, and currently, to their self and partner. Connection was found to positively influence their mental and social wellbeing, through present moment awareness, clarity in their thoughts, accessing memories, and spending time together. The daily integration of music occurred in a variety of ways (i.e., spontaneous, routine, accompanying other activities, just listening) and through various devices (i.e., CD players, radios, computers). For these participants, the day-to-day role of music is as a means for connection – to their self, partner, and the music.

6.3 Contributions to Knowledge

This study provides insight into the growing body of interdisciplinary literature dedicated to dementia, music, aging in place, and contemplative practices. Music has emerged as a key therapy for individuals with dementia as it helps with many of the behavioural and psychological symptoms, most effectively, loss of memory and agitation. This study supports the research on the benefits of music for memory and further suggests that informal, at home, unstructured music can provide similar benefits to structured, formal therapy. Beyond music as a therapeutic intervention to address behavior I suggest offering it as a tool that enriches the lives of persons with dementia and their partners.

Enriching the lives and strengthening the relationship between the person with dementia and their partner are positive aspects of the illness that are missing from most of the literature. The majority of the caregiver literature discusses burnout and depression, and although these are very meaningful and important aspects of a caregiver role, this study suggests there can be caregiver benefit. Findings show that with the use of music, participants expressed their embodied selfhood, supporting the research that claims that a

“self” still exists despite a diagnosis of dementia. This study contributes to the area of embodied selfhood by recognizing that a self still exists within these individuals and further, that this self is recognized by their partner offering the couple an opportunity for connection. Moments of connection become increasingly rare after a diagnosis of dementia; therefore, increased opportunity to recognize and seize these moments is invaluable. Both the expression of embodied selfhood and the opportunity for connection with their partner challenge the idea that with a dementia diagnosis there is only loss.

Contemplative practices are emerging as an important area for health research. Compared to, for example, meditation, mindfulness, yoga, and other practices in the educational setting, music has received little scholarly attention. Findings from this study provide insight into how music may also be framed as a contemplative practice, important to the lives of individuals with dementia. Being aware and living in the present moment is extremely difficult for these individuals. However, music seems to be able to help anchor them (at least temporarily) and as a result, helps these individuals to manage many symptoms of their dementia and connect to their partner.

There has been a tendency in dementia literature to frame music as a panacea. This study supports many of the benefits of engagement with music (connection to self, partner, music, and research) however, I also add that the use of music for individuals with dementia and their partners can be challenging. When music has played a significant role in their life and relationship and, before the diagnosis of dementia, was integrated into their lives with ease, it now can be a reminder of all of the change and loss that dementia has caused. Having to find new, simplified, and effective ways for continuing engagement with music can cause the partners stress and frustration. The decreased ability to perform also causes the individual with dementia similar feelings of loss and discouragement. Critical perspectives of music as a therapeutic solution to dementia, as well as how it is implemented, are important contributions to the area of dementia and music. Personalization is key when turning to tools such as music to enrich the lives of those with dementia. Findings from this study illustrate that maintaining what was meaningful to participants throughout their life, in both type of music and device used, is important. Additionally, for these individuals, a variety of musical devices were used,

none of which were individual listening devices (e.g. iPods), contrary to what the literature states as most effective and common.

This study contributes to the refining of The Psychosocial Model of Music in Dementia (McDermott et al., 2014). The adapted version of this model that I created for this study guided the construction of the research purpose, questions, methodology, and methods used. Additionally, it framed my approach to data collection – the kinds of questions I asked and observations I recorded. However, the findings from these three cases were not thoroughly explained through the use of this framework. Attempting to fit the findings into the predetermined areas outlined in the adapted model limited the findings and neglected key ideas. A more comprehensive and honest depiction of the data was found outside of this model. In particular to this study, an adapted version of The Psychosocial Model of Music in Dementia (McDermott et al., 2014) was an effective guide for the construction of the research and was influential, but less effective as an analysis framework.

The findings of this study also provide methodological insights that are relevant to future research in the area of music and dementia. There is a tendency to ask caregivers of those with dementia to speak on their behalf instead of accessing the insider's perspective. Findings from this study illustrate that there are great benefits to the participants with dementia, their partners, as well as the research itself for their direct inclusion in the study. I support others in their advocacy for the inclusion of people with dementia in research, along with their partners. Data from this study was coproduced from the triad (person with dementia, partner, researcher) and the collective experience was captured. Perhaps this was a more honest depiction of their lives as having only one individual speak on behalf of the relationship (traditionally the partner speaks for the person with dementia) is not representative of their lives, these participants did not live in isolation. Additionally, music and individuals with dementia are most often studied in an institutionalized setting. With the majority of older adults aging in place in the community, I encourage the study of music to occur with these individuals in their homes. Lastly, researchers interested in having their older adult participants use video cameras or other technological devices should be cognizant that they are truly willing and

able to do so. I reaffirm what other researchers have stated about the importance of discussing methodological contributions and insights, especially when it comes to the transformative nature of qualitative research, in the literature, so to inform other researchers in their methodological selection and conduction.

6.4 Future Directions

Based on findings from this study I have identified suggestions for future research in the area of dementia and its practical implications. Researchers should continue to explore the lived experience of individuals with dementia who are aging in place. Population aging and increasing rates of dementia make research in this area ever more relevant and important and the insiders perspective remains limited in much of the research. As this study was limited to these particular cases and this specific context, studies should explore the population of individuals with dementia who are aging in place alone, as well as the area of music and dementia across various genders and cultures. Searching for alternative tools and creative strategies to care for and support older adults to age at home is crucial. This study illustrated the importance of music and connection, therefore studying other alternative strategies (e.g. visual art, meditation, yoga) for individuals with dementia may provide similarly beneficial, useful and timely information. Exploring other alternative strategies can help with understanding what or if there is something unique about the music and dementia connection. Research on strategies for improving at-home care and offering opportunities for connection, has the potential to impact caregivers and decrease caregiver burnout, another important component to allowing individuals to age in place. Organizations such as local Alzheimer Societies would have means to uptake this information and disseminate it to their clients as strategies to improve their overall quality of life. I am confident these suggestions will inform an area of research that will positively enhance the lives of older adults with dementia who are aging in place.

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Appendix A



Article

The role of music in the lives of older adults with dementia ageing in place: A scoping review

Dementia

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Abstract

The number of people around the world living with dementia is predicted to rise from 44 million to 135 million by 2050. Traditional treatments for dementia have been largely unsuccessful and prompted the emergence of alternative strategies. Music is emerging as an effective therapeutic strategy for older adults with dementia however, most of the work to date has focused on institutions. The purpose of this scoping review was to summarize what is known about the role and impact that music plays in the lives of community-dwelling older adults with dementia. Using a five-stage framework for conducting a scoping review, analysis revealed three ways in which music influences the lives of community-dwelling older adults with dementia: (a) reduced agitation, (b) improved cognition, and (c) enhanced social well-being. The concept of personhood provided a lens with which to conceptualize the findings and highlights the need for continued research.

Keywords

ageing in place, community, dementia, music, older adults

Introduction

As of 2015, there is an estimated 46.8 million people worldwide living with dementia (Alzheimer's Disease International, 2015). According to the World Health Organization (WHO, 2015), dementia, as compared to other illnesses and injuries, represents a significant health burden to those aged 60 and above. Currently, the global economic impact of dementia is estimated at \$818 billion US dollars, which represents 1.09% of global GDP (Alzheimer's Disease International, 2015).

Older adults represent the population most affected by this disease; in 2015, 5.2% of individuals aged 60 and older were living with dementia, a number that is projected to

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significantly increase globally over the next 15 years (Alzheimer's Disease International, 2015). Among older adults with dementia, 60–70% are ageing in place in the community, where 80% of the in-home care is provided by family caregivers (Alzheimer's Association, 2012). Caring for a person with dementia takes a physical and psychological toll: up to 75% will develop a psychological illness such as depressive or anxiety disorders, 15–32% will experience depression, and they are at an increased risk for obesity and a weakened immune response (WHO, 2015). As the demands of the caregiving role increase, caregivers are often forced to reduce or quit employment and limit social activity making them vulnerable to social isolation and adding financial stress (Brodaty & Luscombe, 1998; Vitaliano et al., 2005; WHO, 2015).

The desire to remain at home where things are familiar and navigation is easier is strong among older adults with dementia – a person's home reflects their identity, achievements, independence, competence, and self-esteem – factors which are important for maintaining the quality of life, health, and happiness of people with dementia (Gould & Basta, 2013). Delaying institutionalization can have a significant and positive impact on both the older adult and their family. Remaining at home is cost effective, preserves individual privacy, fosters a closer intimate relationship between the person with dementia and their spouse, and provides a more comfortable (physically and psychologically) environment for persons with dementia (Askham, Briggs, Norman, & Redfern, 2007; Finch & Hayes, 1994; Gould & Basta, 2013). As such, there is an established need for accessible, cost-effective strategies that support family caregivers in caring for their loved ones at home, while maintaining their own health and well-being (Hanser, Butterfield-Whitcomb, Kawata, & Collins, 2011).

Pharmacological treatment has been the traditional approach to treating dementia and a common strategy for enabling older adults to remain at home. Drug treatments, however, have been largely unsuccessful and can create a variety of negative side effects including cardiac episodes, accelerated cognitive decline, drowsiness, and a high risk for falls (Park & Specht, 2009). These treatments have not been shown to be effective in alleviating many of the symptoms of dementia – anger, agitation, wandering, psychosis, and/or apathy (Nair, Browne, Marley, & Heim, 2013). Despite this, non-pharmacological approaches are used less frequently than their pharmacological counterparts; 41.9% of people with dementia exhibiting behavioural and/or psychological symptoms have exclusively received pharmacological treatment (Gill & Englert, 2013). Non-pharmacological interventions, such as art therapy, massage, reminiscence, and music therapy, are emerging as new and important approaches to dementia care and treatment. These therapies are described as 'safer' than pharmacological treatments, as they protect against adverse side effects, multiple medication interactions, and limited efficacy (Cohen-Mansfield, 2001; Curtin, 2010). In addition, non-pharmacological interventions aim to address the underlying needs that are causing the inappropriate behaviours instead of masking them with medication, thus increasing the quality of care and providing the means for better communication between caregiver and person with dementia (Cohen-Mansfield, 2001).

Music therapy is not only cost effective and safe but has been found to produce important positive benefits such as enhanced feelings of well-being, increased social interaction, and a heightened sense of empowerment and control (Sixsmith & Gibson, 2007). Music therapy is the use of music to promote, maintain, and restore mental, physical, emotional, and spiritual health (Canadian Association for Music Therapy (CAMT), 1994). Individuals with dementia often respond to this form of therapy (Foster, 2009) as, we now understand, parts of the brain required for the processing of musical information remain intact in individuals with

dementia (Davidson & Fedele, 2011; Foster, 2009). Music is also utilized with this population outside of standard therapy protocols through involvement, for example, in community choirs or the iPod Project. Choirs have been shown to foster social cohesion, decrease anxiety, and provide an overall positive experience for individuals with dementia (Clements-Cortes, 2013; Harris & Caporella, 2014). While there is no empirical evidence to date, the *Music and Memory iPod Project*, a non-profit organization that brings personalized music into the lives of the elderly through digital music technology (<http://musicandmemory.org>), reports similarly strong results reconnecting them with the world through music triggered memories and improved quality of life (Scully & Rossato-Bennett, 2014).

Music in institutions

The majority of published literature in the area of dementia is focused on long-term care facilities. Findings from this research illustrate music can positively affect individuals with dementia in a variety of ways including decreased agitation, prompting memory, increasing engagement (Gill & Englert, 2013), decreasing depression (Chu et al., 2014), facilitating the building of relationships (McDermott, Orrell, & Ridder, 2014), enhancing communication (Sixsmith & Gibson, 2007), and overall improvement in the quality of life (Sakamoto, Ando, & Tsutou, 2013). Music in this research is predominantly delivered through structured and professional-led music therapy protocols. For example, group music therapy sessions led by a trained music therapists and attended by multiple residents in a long-term care facility (Chu et al., 2014; Gill & Englert, 2013; Sixsmith & Gibson, 2007); focus groups with music therapists, care home staff, and day hospital clients (McDermott et al., 2014); the supervised playing of instruments in active music therapy (McDermott et al., 2014; Sakamoto et al., 2013); instructor-led group singing sessions (Davidson & Fedele, 2011); and individualized music therapy with personalized music and paired activities (Gotell, Brown, & Ekman, 2009).

The impact of music therapy on people with dementia living in institutional settings (e.g. long-term care, nursing homes, etc.) is well documented in the literature. Reviews include, for example, *Group music interventions for dementia-associated anxiety: A systematic review* (Ing-Randolph, Phillips, & Williams, 2015), *Review of the effect of music interventions on symptoms of anxiety and depression in older adults with mild dementia* (Petrovsky, Cacchione, & George, 2015), and *Music therapy for service users with dementia: A critical review of the literature* (Blackburn & Bradshaw, 2014). Authors of these reviews report music is a safe and inexpensive intervention that benefits those with dementia in numerous ways. For example, they have found that music is a promising strategy to reduce agitation and anxiety, along with improving the quality of the interaction between the individual and their caregiver, thus improving lives of older adults with dementia (Blackburn & Bradshaw, 2014; Ing-Randolph et al., 2015; Petrovsky et al., 2015).

Authors conclude with a call for more research in this area in order to promote wide-scale implementation of music in the lives of this population (Blackburn & Bradshaw, 2014; Ing-Randolph et al., 2015; Petrovsky et al., 2015). Overall the literature illustrates the majority of research is focused on institutionalized settings (e.g. long-term care facilities) and structured professional music therapy interventions. Much less is known about music among community-dwelling older adults. The purpose of this scoping review is to help fill this knowledge gap by examining what is currently known about the role and impact that music plays in the lives of older adults with dementia who are ageing in place.

Method

As an alternative to a systematic review, scoping reviews focus on systematically charting a broad area of research with the aim to present a general sense of what is known while identifying significant gaps in the existing literature in this topic area (Arksey & O'Malley, 2005). Scoping reviews have been effectively used to summarize various topic areas such as the literature on stroke rehabilitation, assistive technologies, and self-management for people with dementia and highlight gaps in these areas (Gibson et al., 2014; Mountain, 2006; Nelson et al., 2015). Unlike a systematic review, which provides a detailed description of individual studies, the scoping review does not focus on assessment of included studies but instead is concerned primarily with summarizing the main, overarching findings and identifying gaps in the existing research literature (Arksey & O'Malley, 2005). Arksey & O'Malley's five-stage framework for conducting a scoping review served as the guide for this review:

Stage 1: Identifying the research question. What is the role and impact of music on the health and well-being of older adults with dementia who are ageing in place?

Stage 2: Identifying relevant studies. The following key search terms were used in varying combinations in order to identify relevant literature: 'dementia', 'Alzheimer's disease', 'music', 'music therapy', 'ageing in place', 'home', 'in home', 'community', 'community dwelling', and 'house'. Ten electronic databases were utilized: Ovid-MEDLINE, Web of Science, Ovid-PubMed, CINAHL, PsycINFO, ProQuest, Library & Archives Canada-Theses Canada, Brock University Theses & Dissertations, University of Toronto Thesis Depository, and ProQuest Dissertations & Theses Global. This search process generated 444 articles.

Stage 3: Study selection. The third stage outlined study selection through the generation of inclusion and exclusion criteria. Abstracts were reviewed to determine their relevance with the identified research question. Studies were excluded if:

- they were not available in English;
- all study participants resided in institutions;
- they focused primarily on another disease (i.e. Parkinson's disease).

Age was not used as a selection criterion as dementia is a disease associated with an older adult population and the literature search returned no results with younger participants (>58 years). Application of these criteria resulted in a total of 17 articles: seven mixed methods, seven quantitative, and three qualitative (see Appendix 1 Table 1).

Stage 4: Charting the data. The fourth stage involved a process of organizing and charting the data, which was achieved through the construction of a data summary table (see Appendix 1 Table 1 for a shortened version). The selection and categorization of characteristics within the table was informed by the literature. Categories were identified using characteristics that were comparable across studies: study methodology, methods, intervention and protocol, sample, factor of interest, and findings.

Stage 5: Collating, summarizing and reporting the results. This was achieved as follows:

1. Study characteristics were identified through multiple readings of each article.
2. Characteristics were organized and re-organized into a summary table.
3. Data in the summary table were coded according to 'factors of interest', the outcomes of interest as identified by the researchers prior to the research, others that emerged through the research, and also those highlighted in other literature within this field.

4. Similar codes were combined and renamed to better describe overall categories.
5. Categories were reviewed and organized to highlight key themes.
6. Themes were interpreted in order to produce study findings and identify research gaps in the topic area.

Results

Analysis revealed three key ways in which music influences the lives of non-institutionalized older adults with dementia: reduced agitation, improved cognition, and enhanced social well-being. Findings related to these factors are summarized below and highlight those that are shared between studies, in addition to identifying unique findings (i.e. reported in one study only). A fourth key theme to arise from the analysis was the way in which music also positively impacted the lives of the informal caregivers. It was also found that the research includes a broad range of musically informed intervention strategies that have been used with people with dementia, including personalized CDs, playing instruments, dancing, and songwriting.

Agitation

Agitation is commonly evaluated in research that explores the effect of music on people with dementia; in this scoping review four of the 17 studies (almost 25%) examined agitation. Agitation, which is popularly defined by Cohen-Mansfield and Billig (1986) as 'inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual', is a common symptom of dementia, with 24 98% of people diagnosed experiencing agitation at some point during their illness progression (Ledger & Baker, 2007). Agitation is expressed in numerous ways, as violence, pain, restlessness, complaining, or unwarranted attention seeking (Park & Specht, 2009). All musically informed intervention strategies in this review have been described as producing positive effects on agitation including improving relaxation, increasing attention span, decreasing pain, and improving social skills. These changes in behaviour are most commonly measured quantitatively, using scale ratings that are completed by a third party.

In this review, three of the studies assessing agitation were quantitative (Brotons & Marti, 2003; Park, 2010; Park & Specht, 2009) and one was a mixed method study (Yasuda et al., 2006). All of the quantitative studies utilized the Cohen Mansfield Agitation Inventory (CMAI) to measure the construct of agitation, in combination with other scales used to measure associated factors (i.e. Neuropsychiatry Inventory, Mini-Mental State Examination, Modified Pains Assessment in the Demented Elderly). Similar to the majority of these scales, the CMAI is completed by a third-party observer, such as a caregiver. All of these studies conclude that music is an effective means to reduce agitation in its various embodied forms of violence, pain, and abnormal behaviour (Brotons & Marti, 2003; Park, 2010; Park & Specht, 2009; Yasuda et al., 2006). In the mixed method study, researchers implemented personalized music interventions in three different cases of individuals with dementia who were living at home (Yasuda et al., 2006). Each intervention included personalized music selections and output messages played from a recorder. Researchers similarly found that music is successful in reducing behavioural disturbances including agitation, verbal abuse, and aggression.

One of the studies that assessed agitation stood out as unique as it implemented an eight-week intervention that had older adults listening to preferred music for 30 min, two times per week, for two weeks, followed by no music for two weeks (Park & Speccht, 2009). The intervention attempted to include the person with dementia's perspective through the use of an Assessment of Personal Music Preference before creating the individualized CDs. Most research in the field of music and dementia does not incorporate the person with dementia's preferences, unless assumed by a third party. The findings from this study were mirrored by those from Park (2010) and demonstrate that agitation levels are significantly reduced after listening to 30 minutes of music.

Cognition-memory

Memory, as a key aspect of cognition, is a central focus of the literature reviewed. Other cognitive aspects include orientation, attention, concentration, language, abstract reasoning, judgment, and visual construction (Li et al., 2015). In terms of the memory and music literature, implicit and explicit memory are discussed where explicit memory is responsible for the personal and emotional connection that can be elicited by certain melodies or lyrics, and implicit memory is important for the skills used to play a musical instrument (Cowles et al., 2003; Kerer et al., 2013; Vanstone & Cuddy, 2009).

Analysis revealed that among the literature reviewed, music is seen to positively influence the memory of older adults with dementia who are ageing in place. The effects that music has on an individual's memory ranged from being able to recognize familiar tunes and perform musical tasks, to accessing old memories associated with specific music.

Results from four methodologically diverse studies indicate that despite a dementia diagnosis, the ability to perform musical tasks, and the ability to remember and connect old tunes with memories among the older adult population, can be preserved. For example, using a case study methodology authors described how an 80-year-old violinist with Alzheimer's type dementia was able to learn and have partial memory of a musical composition he had not known pre-diagnosis. Based on these findings the authors suggest that the ability to learn a new song depends on neurological components independent of explicit memory (Cowles et al., 2003).

Kerer et al. (2013) tested explicit memory using music in 43 participants, 10 of which had dementia. Results showed that individuals with dementia were able to detect distorted tunes more often than their counterparts in the control group. These findings support the notion that there is a specialized explicit memory system for music which is distinct from other cognitive domains (Kerer et al., 2013). In other work, researchers studied 24 older adults (12 controls, 12 with dementia with all but one living in the community) to determine recognition memory for familiar tunes and the ability to identify manipulated distortions in said tunes (Vanstone & Cuddy, 2009). Findings describe a high degree of variability in the capacity to perform musical tasks involving memory in older adults with dementia, from full capability to none at all. Additionally, results indicate no consistent relation between musical capability and level of dementia suggesting the need for further research into implicit memory and music (Vanstone & Cuddy, 2009).

In addition to building new memory, music was also seen to facilitate access to and validate participants' old memories. For example, Hays and Minichiello (2005) collected qualitative data through the use of in-depth interviews and focus groups with 52 adults, aged 60 years and over (some with dementia and some without) to explore the meaning of music

in their lives. Using a life history approach they identified key themes connected to the meaning of music for older adults with dementia. Examples of these themes are: identity and understanding of self; connection: self and others; and well-being, therapy, and health. Illustrating their findings, the researchers quote a participant who used music as therapy at home with her husband who had dementia: 'Through the war years we danced a lot and he remembered the old tunes, and of course we shared them a lot in our later years' (Hays & Minichiello, 2005, p. 443).

In addition to memory, music therapy was also found to positively influence abstract thinking (i.e. the ability to deal with concepts), among the described population. Results from a case control study evaluating the effect of home-based music therapy on the cognition of people with Alzheimer's disease who were under usual pharmacological treatment showed abstract thinking was significantly improved in the music therapy group, with no significant differences in other cognitive domains (Li et al., 2015).

Social well-being

Social well-being as described within this literature includes engagement, support, connection, and communication with other individuals (most commonly spouse). Sixsmith and Gibson (2007) use the ecological model of well-being (Torrington, 2006) to define this construct in terms of everyday activities of the person, and how a person derives meaning from these activities as central to their well-being. Positive well-being includes happiness and life satisfaction. For the purpose of this review, well-being is described as exploring the meaning a person might ascribe to their experiences with music. Overall, the literature reviewed demonstrates that music positively impacts the social well-being of community-dwelling older adults with dementia. In particular, music was seen to support social relationships, improving the relationship with the caregiver as well as increasing opportunities for interaction, connection, and engagement with others.

Three studies using various methodologies and methods similarly conclude that music interventions provide an opportunity for the person with dementia to continue to engage with their caregiver in similar ways to what they had prior to a diagnosis (Clair, 2002; Clair, Tebb, & Bernstein, 1993; Hays & Minichiello, 2005). For example, Baker, Grocke, and Pachana (2012) implemented a six-week active music intervention where the caregiver was responsible for using music to facilitate interaction with their spouse. Results were positive as caregivers in the study describe: '...just being able to be together and enjoy and listen to something we both love is a benefit. To share something is a good thing and this is still something we want to do and are able to do...' (Baker et al., 2012, p. 12).

Music helped not only to facilitate communication but was also used as an alternative to verbal communication. This approach acknowledges the person with dementia's perspective and provides them with an alternative way to connect and communicate with their caregiver. This is particularly useful when verbal language is difficult or not possible (a common challenge among people with dementia). For example, researchers describe how the making of music, through singing or the playing of an instrument, was an effective method of expressing one's emotions without the use of words (Hays & Minichiello, 2005).

In contrast to the studies that made conclusions about mutuality but did not include measures to capture the perspective of the person with dementia, three studies used methods and processes that succeeded in obtaining this perspective. Two of these studies explored the 'Singing for the Brain' (SfTB) programme in different locations and through different methods.

SftB is a programme established by the Alzheimer's Society in the United Kingdom that combines aspects of reminiscence therapy and music in a group, sing-along environment (http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=760). Reporting from an insider's perspective, these studies similarly found that music has the capacity to act as a catalyst for building relationships and support, as well as connecting people through a shared experience and social inclusion (Hara, 2011; Osman, Tischler, & Schneider, 2014).

Caregivers

Caregivers play an important and diverse role in the lives of people with dementia. As a group, caregivers of those with dementia tend to be family members, and oftentimes they are old and frail themselves (Pickard, 1999). Although caregiving can ultimately be a rewarding experience, those who care for individuals with dementia are susceptible to stress, depression, and overall burnout (Lewis, Bauer, Winbolt, Chenco, & Hanley, 2015). These negative health factors accumulate causing the caregiver to institutionalize their loved one (Argimon, 2004). Findings from this review illustrate that beyond benefiting the individual with dementia, music positively impacts caregivers by increasing self-esteem and decreasing anxiety, agitation, and loneliness.

Using a mixed method study, for example, researchers tested a caregiver-administered music programme to determine whether it improved caregivers' mood and psychological state while simultaneously decreasing their distress (Hanser et al., 2011). As instructed by the music therapist, the caregiver and person with dementia listened aloud to a track(s) from their personalized CDs, three days per week, while simultaneously engaging in a therapist instructed activity such as, reminiscing, exercise, movement, or discussion. Results revealed that while both members of the dyad showed increases in the areas of relaxation, comfort, and happiness, the caregiver response was more significant.

Similarly, Lewis et al. (2015) explored the effect of individualized music (an MP3 player) on caregiver stress in an informal homecare setting. Their findings also confirmed that while this kind of personalized intervention had a calming effect on the person with dementia, it had an even greater effect on reducing caregiver's stress, even though they were not the one's wearing the device. With time-use diaries researchers reported that 46% of entries were related to chores, cooking, shopping, and outdoor activities, while 29% were associated with relaxation, socializing, and personal time; all of which indirectly contributed to reducing the stress of the caregiver (Lewis et al., 2015). Caregiver anxiety was also reduced in an intervention study where a professional-led group music therapy session was integrated into a rural home environment (Brotons & Marti, 2003). Sixty-seven per cent of caregivers in this study stated that music therapy offered them an unique space that they ordinarily would not have access to, to share and express feelings (Brotons & Marti, 2003).

Caregiver's loneliness and self-esteem was assessed as part of the Clair et al. (1993) study. While there were no statistically significant results to report, over the course of the music therapy intervention, caregivers were exposed to new resources that they reported had the potential to improve their relationship with their loved one with dementia, for example, using music in ways such as singing, drumming, and dancing. Consequently, these resources were found to positively impact their feelings of loneliness and self-esteem (Clair et al., 1993).

One notable finding among this literature was that although the psychological well-being was seen to improve in both caregiver and care receiver, caregiver satisfaction was found to

decrease over the course of the study (Hanser et al., 2011). This dissatisfaction was mostly accredited to the challenge the caregivers experienced in leading the musical sessions on their own without the help of the therapist, after a two-hour training session between caregiver and music therapist, the caregiver was then left to conduct the following numerous sessions on their own. This finding highlights a need for flexible, sustainable, and more natural ways to incorporate music into the everyday lives and homes of this population.

Discussion

The focus of the literature on the impact of music interventions for minimizing agitation, improving memory, and enhancing relationships among older adults makes sense for several reasons. First, these characteristics are some of the most commonly affected and reported. In addition (according to the literature), agitation, memory, and social relationships, are factors that are significantly impacted by the use of music. In particular to the home environment, these three factors represent areas that are essential in improving the quality of care and the feasibility of ageing in place. Music, as an inexpensive and accessible alternative therapy, has been shown to be effective in supporting older adults with dementia in their home environment. This support extends to the informal caregivers in these homes as well. Consideration of how music also influences these caregivers is similarly important as caregiver burnout among this population is significant, and strategies that are simple and effective for them to implement are needed; music has been shown to be an effective strategy in relieving caregiver stress and improving their relationships with their loved ones.

In reviewing the literature it is not only important to consider what is there, but also what is missing. This review serves to highlight several gaps: (a) a narrow range of methodologies and methods, (b) the predominant use of structured music interventions and protocols (therapies), and (c) the lack of an insider's (person with dementia's) perspective.

Methodologies/methods

Most of what we know about the impact of music on the lives of older adults with dementia comes from quantitative research designs; seven of the 17 studies in this review were explicitly quantitative in nature, and when mixed method designs were employed, (seven of the 17), the quantitative data were prioritized (i.e. given more value and discussed at greater length than the qualitative data). Quantitative research provides us with important knowledge about neurological state and change; medication levels; recall ability; and scales regarding pain, agitation, and depression, however what is missing is important social and contextual factors (such as engagement, well-being, meaning, self-awareness, and support). The quantitative studies reviewed conceptualize music as a therapeutic tool and use a biomedical approach and language when conceptualizing dementia. Listening to music, however, is more than a therapeutic tool or intervention; music is a significant component of the everyday lives of many people, including, people with dementia (Sixsmith & Gibson, 2007). There has been some suggestion that the impact of music extends far beyond the aforementioned characteristics to include meaning, as a strategy to hold onto identity, and overall well-being and happiness. A quantitative approach, however, is not well suited to this kind of inquiry. There is need for qualitative research in this area of music and dementia, to go beyond the biomedical and caregiver perspective and concentrate solely on the role and influence that music has on the everyday life of the older adult with dementia.

Structured music therapy

Structured music protocols are implemented and evaluated in the majority of research conducted in the area of music and dementia. These interventions are often coordinated by professional music therapists and have defined time guidelines and routines, in terms of whether individuals are supposed to be listening to music, playing instruments, dancing, or singing along to songs. This technique is evident in the literature on institutionalized individuals as well as prevalent in the smaller amount of literature on informal at-home care. Although many of these interventions have been proven to be successful in targeting specific behaviours in individuals with dementia, concerns have been raised about the long-term feasibility of these interventions; informal caregivers report challenges with maintaining structured, formal sessions on their own. This highlights the need to identify and research more natural and flexible ways that music can be integrated into the lives of people with dementia who are ageing in place.

Insider's perspective

The insider's perspective is missing from much of the literature on music and dementia. This is reflected in the repeated incidences of caregivers' perspectives prioritized over the perspectives or actions of those with dementia. For example, quantitative measures of behaviour are assessed by a third party (Brotons & Marti, 2003; Park, 2010; Park & Specht, 2009), and when factors regarding social well-being were explored (and conclusions made about the relationship), the caregiver perspective was the main source of information (Baker et al., 2012; Clair, 2002; Clair et al., 1993). Most commonly, caregivers are asked, or expected, to be the voice for the person with dementia. This is understandable when communication with these individuals is no longer an option because of their illness progression, but this reliance on the caregiver becomes more of a problem when communication with the person with dementia is still feasible, and when we do not look for alternative ways to examine these issues (e.g. visual communication, observation, artistic expression). A consequence of targeting caregivers and others (i.e. medical professionals, therapists, or other family members) is the loss of the perspectives from the 'real experts' on this phenomenon (i.e. the individuals with dementia themselves). This loss results in not knowing what interventions are resonating, what aspects of music are most important or relevant, and represents a missed opportunity to validate their personhood and improve the person-centred care of these individuals.

Others have argued that dominant conceptualizations of persons with dementia focus on the embodiment of the illness with little or no recognition of individual agency or personhood. The seminal work of Kitwood (1997) describes how personhood is directly linked to identifying one's self-worth and dignity, and how with a diagnosis of dementia individuals are often treated and cared for in ways that depersonalize and infantilize, ultimately leading to a loss of personhood that is often only associated with the neuropathology alone (Kontos & Naglie, 2007). Personhood in music therapy, is often linked to an individual's musical identity, framed by their past life experiences, both personal and cultural, and the particular era with which they associate (McDermott et al., 2014). In dementia care, personhood represents a new perspective that opens up opportunities to develop more holistic and sympathetic care practices (Kitwood, 1997; Kontos, 2005). A personhood approach promotes better understanding of and communication with individuals with dementia. In addition, personhood challenges the idea of a loss of selfhood in dementia and thus decreases the stigma around this illness.

Identifying if or how music can aid in bringing forth and acknowledging the personhood that remains in older adults with dementia will be a critical component of improving the lives of individuals who are ageing in place in the future.

Conclusion

Given population ageing trends and rising incidence rates of dementia, alongside its chronic nature and the ability to live a long time with the diagnosis, it is crucial for alternative therapy strategies to be created and utilized with this population. Music has been shown to be an accessible and effective alternative therapy for people with dementia, both in an institutional setting and in the home. The results of this scoping review support previous research to demonstrate the benefits of music in the lives of people with dementia and make an important contribution by focusing on individuals who are ageing in place, a population that prior to this scoping review had not been examined in this way. It is important to further explore emerging personhood research as it represents a humanized and compassionate strategy to support older adults with dementia who are ageing in place and those who care for them.

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Author Biographies

Melanie Elliott is a Master of Arts candidate in Applied Health Sciences at Brock University. She volunteers at the Room 217 Foundation that is dedicated to caring for the whole person with music. Melanie is passionate about improving the lives of older adults through innovative recognition of their personhood. Her research interests include older adults and their experience of dementia, music and health, and maximizing quality of life.

Paula Gardner is an Assistant Professor in the Department of Health Sciences at Brock University and a Research Scientist at Bridgepoint Collaboratory for Research and Innovation. Paula has a PhD in Public Health from the University of Toronto and an active programme of research examining healthy ageing from a community-based perspective. She is an educator, gerontologist, and advocate committed to promoting the health, happiness, and quality of life of older people. Paula has published her work in books and journals and presented nationally and internationally.

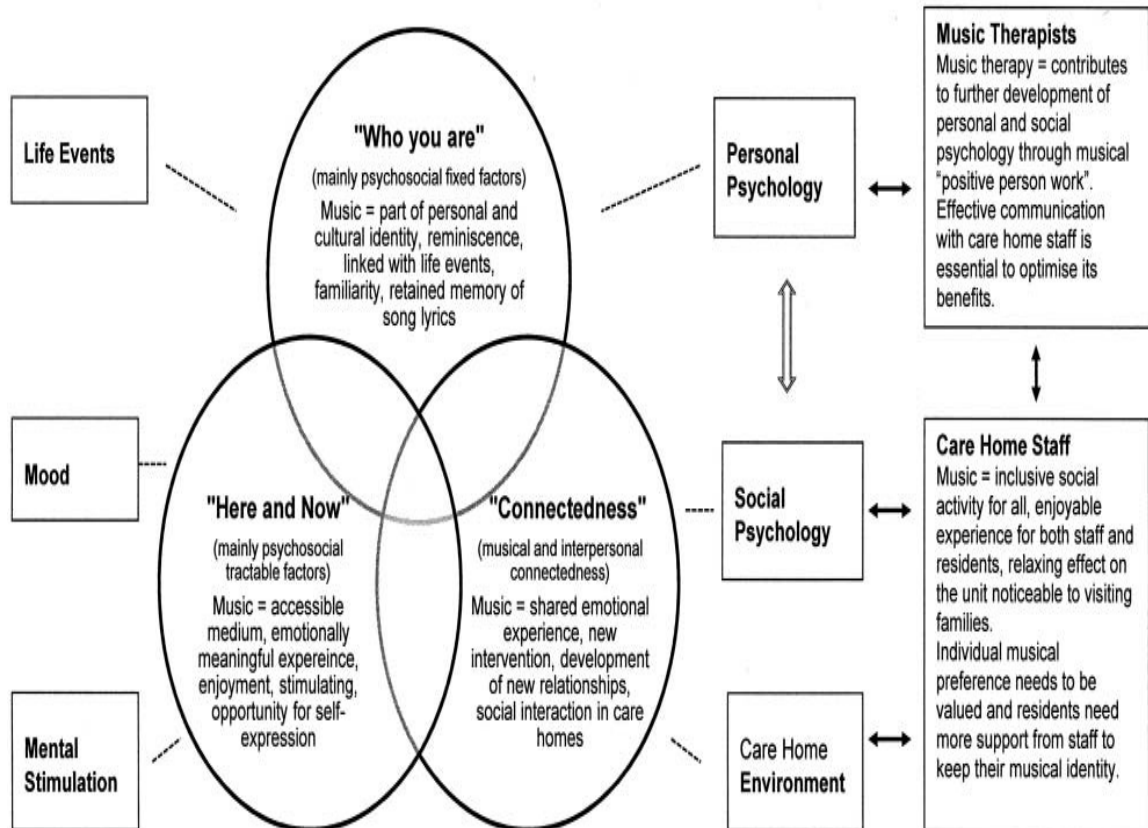
Appendix I

Table 1. Data summary (short version) – studies used in the review.

Authors	Year	Design	Methodology	Factor	Age (years)	Time
Baker, Grocke, and Pachana	2012	Mixed	Concurrent triangulation design	Couples well-being	59–88	Six weeks
Brotons and Martí Clair	2003 2002	Quantitative Quantitative	Pilot study Experimental design	Agitation, caregiver burden Engagement – participation, verbal interaction, touch	M = 75.67 67–82	12 days Eight weeks
Clair et al.	1993	Mixed	Pilot study	Loneliness and self-esteem of the caregiver, couples well-being and engagement	65–76	Six weeks
Cowles et al.	2003	Quantitative	Case study	Musical skill/memory	80	Three months
Hanser et al.	2011	Mixed	Applied behaviour analysis (AB) design	Mood and psychological state of persons with dementia, caregiver distress and satisfaction	76 >	N/A
Hara	2011	Mixed	Ethnography	Support	Late 60 s–mid 80 s	Six months
Hays and Minichiello	2005	Qualitative	Life history approach	Personal meaning and memory of music, connection and communication	60–98	N/A
Kerer et al.	2013	Quantitative	Not provided	Explicit/semantic memory	M = 79.4	N/A
Lewis et al.	2015	Mixed	Quasi-experimental design	Mental health, well-being and coping capabilities of carers	30–70 > (carers)	Four weeks
Li et al.	2015	Quantitative	Case-control study	Cognition	M = 76.7	Six months
Osman et al.	2014	Qualitative	Not provided	Health and well-being of the couple	N/A	Two months
Park	2010	Quantitative	Quasi-experimental design	Pain in persons with dementia and agitation	60 > (most 81–90)	Eight weeks
Park and Specht	2009	Quantitative	Pilot study	Agitation	60 > (60–98)	Eight weeks
Sixsmith and Gibson	2007	Qualitative	Not provided	Well-being	62–96	N/A
Vanstone and Cuddy	2010	Mixed	Case-control study	Memory	M = 81.5 (77–86)	1–3 days
Yasuda et al.	2006	Mixed	Experimental design	Behavioural disturbances – violence, agitation, verbal abuse	71, 68, 75	2/3/4 weeks

Appendix B

The Psychosocial Model of Music in Dementia (McDermott et al., 2014)



Appendix C
Music Lessons Recruitment Flyer



HELLO,

My name is **Melanie Elliott** and I am a Master's student at **Brock University** in the faculty of Applied Health Sciences, with a concentration in **Community Health**. I am conducting a research study to explore the role of music in the lives of individuals with dementia who are living in the community.

I am looking for volunteers to participate in the study. Your participation will involve me coming to your home and talking to you. It will also involve me observing and videotaping some of your daily activities including listening to or making music in your home.

Are you, or someone you know:

- Experiencing the beginning stages of dementia?
- Residing at home in the community?
- Living anywhere between the Niagara and Durham Region?
- Listening or making music on a regular basis?
- Willing to be interviewed?
- Willing to be observed?
- Willing to be videotaped?

If you said **YES** to all of these questions and you would like to find out more information or volunteer to be apart of this study please call:

Melanie at: 289-385-6706

THANK YOU!

Appendix D
Music Lessons Information Sheet



Who I Am:

My name is Melanie Elliott and I am a Master's student at Brock University. I am in the Department of Applied Health Sciences in the Community Health stream. My academic background is in health studies and biology.

The overall goal of my research is to support the health and wellbeing of older people. In this project I want to understand the role of music in the lives of individuals with dementia who are living in their homes in the community.

What I Want to Do:

I want to talk to people with dementia who live anywhere from the Niagara to the Durham Region. I want to meet with them in their homes on several occasions (3), ask them questions about their experiences and observe them during some of their daily activities, including listening to or making music. I will tape record these conversations and take videos of them while listening to or making music.

I will use this information to understand the role that music plays in the lives of people with dementia living in their own homes. I am looking for individuals from all kinds of different backgrounds and experiences.

Who Can Participate:

Anyone who has recently been diagnosed with dementia, is living

in their home anywhere from the Niagara to the Durham Region, and who listens to or makes music on a regular basis. They must also be willing to be videotaped.

What You Have to Do:

My visits will last between 1 and 2 hours – it is really up to you! During our conversations I would like to tape record what you say so that we can remember it for later. If at any point during the project you decide that you want to stop or do not want to be a part of the research or have any questions at all – all you have to do is say so!

Participation is completely voluntary. Nobody will be upset with you if you decide you do not want to participate and want to withdraw from the project. All the information you give us will be strictly confidential although you will, of course, be identifiable in some of the videos.

Why You Would Want to Volunteer:

This experience has the potential to enrich your own understanding of the role of music in your life and provide you with an opportunity to share your past and present experiences of music. Additionally, the knowledge you provide will benefit the academic community and help us better understand the role of music in dementia.

If you ever have any questions about the project you can always call me at 289-385-6706 (melanie.elliott@brocku.ca) or Paula Gardner at 905-688-5550 Ext. 6176 (paula.gardner@brocku.ca).

Appendix E

Music Lessons Semi-Structured Interview Guide



The interviews will have a conversational and informal nature, and will be ultimately guided by the research questions. The first one-hour interview will cover the areas listed below through the use of the outlined open-ended questions. Prompts in the form of specific topics that I am hoping to explore are also provided. The second interview is a follow-up to interview one and will provide an opportunity for: clarification, asking new questions that address any gaps, prompting for more information on particular topics, address any missed topics or questions, and elaboration on any interesting points.

The key areas of information I am hoping to gain through these interviews are:

- Life story with music (change over time)
- Meaning of music to them and their life
- Practical details and types of music
- The day-to-day role of music
- The influence of music on health and wellbeing

1. Could you begin by telling me about music in your life

a. Life story with music

- i. The role that music played in your life as a child/teenager/adult/now
- ii. Meaning- *What is it about music specifically that you enjoy? What does music do for you that other things can't?*
- iii. Importance- *Explain/describe the importance of music to you.*

- iv. Feeling- *How does music make you feel? Emotional/inspired/escaping from reality? Can you describe these feelings.*
- v. Memories associated with specific songs/genres/artists? *Describe these memories and the feelings associated with them.*
- vi. Connection- *How/does music affect your relationship with others?*

b. Practical uses and types of music

- i. Devices- *Stereos, iPods, radios, sound systems- Why is this one your favourite?*
- ii. Instruments- *Why the interest in this particular one? How long have you been playing?*
- iii. Types- *Favourites, genres, dislikes, artists, songs- Why? Tied to any memories or particular feelings?*

c. Day-to-day role of music

- i. Typical day highlighting points during the day when/where you're using music
- ii. Frequency of use- *Scheduled or spontaneous? Why?*
- iii. Time of day- *More common than others? Why?*
- iv. Accompanying activities- *Describe and why?*
- v. Social- *Listening/playing alone or with others? Why?*
- vi. Health- *Does music help you in any way in your life? Rely on it? How?*

Appendix F
Music Lessons Participant Consent Letter



Contact Information:

Principal Investigator (PI): Melanie Elliott, MA Candidate
Department of Applied Health Sciences
Brock University
289-385-6706
melanie.elliott@brocku.ca

Faculty Supervisor: Paula Gardner, PhD, Assistant
Professor
Department of Applied Health Sciences
Brock University
(905) 688-5550 Ext. 6176
paula.gardner@brocku.ca

1. I understand that the purpose of this research is to explore, from my perspective, the role of music in my life.
2. I know that my participation in this study is voluntary. I can withdraw at any time, and if I do so all study data up to this point will be destroyed. I understand that I do not have to respond to any questions that I do not wish to answer. I know that my participation

involves the following steps:

- a. a chance to ask questions about the study and my role
 - b. signing this consent form
 - c. taking part in 3 conversations in my home each lasting 1-2 hours and answering questions about my present and past experiences of music
 - d. being observed in my home during some of my daily activities and while listening to music
 - e. being videotaped
 - f. completing a personal information survey (ie. name, age, gender etc.)
3. I understand that our conversations will be audio taped and transcribed word-for-word.
 4. I understand that all the information I give will be kept confidential. Pseudonyms will be used in all published reports and presentations. I also understand that I will be identifiable in the videos. No one but the researcher and her supervisor will have access to the study information and all of the audiotapes, transcripts and videos will be kept under lock and key.
 5. I understand that there are possible benefits of my participation that include providing an opportunity for

me to discuss my enjoyment of music while enhancing the academic knowledge on the perspectives of individuals with dementia.

6. However, I also understand that there are limited risks associated with my involvement in this study. These foreseeable risks are the potential to bring up emotional past experiences and memories that may make me feel uncomfortable.
7. I will receive a copy of this Consent Form and I know that I can ask more about the study if I wish at any time.
8. I am aware that I will not be compensated in any form for my participation in this study.
9. The study has been explained to me, I have been given an opportunity to discuss it and my questions have been answered to my satisfaction. I understand my role and that I am free to leave at any time.

If you have any questions about this study or require further information, please contact Melanie Elliott or Paula Gardner using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University. If you have any comments or concerns about your rights as a

research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

- ☐ Check this box if you agree to be audio-recorded.
- ☐ Check this box if you agree to be videotaped.
- ☐ Check this box if you agree to have images and videos used publicly in research presentations and publications.

Name:

Signature:

Date: _____

Appendix G

Music Lessons Observation Guide

Questions that guide the observation of the participant and their environment:

- What evidence/artifacts are in the home environment that demonstrates their connection to music?
- How does music make them feel? (Observable emotion and movement)
- What is the role that music plays in their life, and has this role changed? (Personal identifiers)
- How is music integrated in their day-to-day lives? (Room layout)

What to Look For	Examples	Notes
Artifacts related to music	Stereos, posters, earphones, MP3 players, records, CDs, instruments etc.	
Expressions when talking about/listening to music	Tears, smiles, frowns, excitement etc.	
Personal identifiers related to music or otherwise	Tattoos, blisters, jewelry, clothing etc.	
Room layout	Speakers on walls/floor, surround sound system, room for musical activities,	

	piano/guitar in corner of the room etc.	
Physical Movement	Dancing, tapping feet/hands, clapping hands, snapping fingers, other physical gestures	
Other		

Appendix H
Music Lessons Video Guide



What Could I Videotape?

As part of the *Music Lessons* study you have agreed to videotape yourself engaging in music in some way, shape, or form.

Instructions: Use the video camera 4-5 times each time lasting between 2-10 minutes.

Just a reminder: There are instructions on how to use the video camera inside of the camera case.

Here's a list of examples of things that you can videotape over the next week (before I return):

1. You listening to music while relaxing at home
2. You playing an instrument (if you do)
3. You dancing to music (alone or with someone)
4. You listening to music while doing the dishes or cooking
5. You making music with objects in your home (e.g., spoons, clapping, tapping, snapping fingers)
6. You singing
7. You singing while doing other activities at home

Appendix I
Music Lessons Personal Information Survey



Name: _____

Gender: _____

Age: _____

Place of Residence: _____

How long have you lived here? _____

Do you live alone or with others? _____

When did you receive the dementia diagnosis? _____

Are you on any medication related to dementia? _____

Do you participate in any alternative therapies? _____

Appendix J
Music Lessons Telephone Script

Hello _____,

Thank you for calling, I appreciate your interest in participating in the 'Music Lessons' Research Study.

I would like to ask you a few questions just to make sure all of the research criteria have been met. Is that OK?

1. Have you been diagnosed with dementia?
2. Do you live in the community?
3. What is your address?
4. Do you listen to music at least twice a week?
5. Are you enrolled in any type of music therapy program?
6. Are you willing to be videotaped?
7. Would you be willing to take your own videos? I will show you how to use the camera if you like – it's not a fancy camera, just a simple 'point and shoot'.

Thank you so much for answering my questions.

a) You meet all of the criteria, and so I would like to invite you to participate in the study. Do you have any questions for me? Can we arrange a time for a first meeting so we can meet personally and I can go over the study and get you to sign a letter of consent? What is your telephone # and address?

OR

b) I'm sorry, I really appreciate your interest but for THIS particular study your situation doesn't quite fit. But if you are interested in volunteering for other projects, I'd be happy to keep your name and telephone # on file?

Appendix K

Music Lessons Newsletter Recruitment



My name is **Melanie Elliott** and I am a Master's student at **Brock University** in the faculty of Applied Health Sciences. I am conducting a research study to explore the role of music in the lives of individuals with dementia who are living in the community. I am looking for volunteers to participate in the study. Your participation will involve me coming to your home and talking to you. It will also involve me observing and you videotaping some of your daily activities including you listening to, playing, or making music in your home. The information you provide will benefit your own understanding and the academic community because you are the real experts on this phenomenon, and help us better understand the role of music in dementia.

Are you, or someone you know?

- Experiencing dementia?
- Residing at home in the community?
- Living anywhere in the Toronto area?
- Listening to, playing, or making music on a regular basis? (Regular part of your life)

If you said **YES** to all of these questions and you would like to find out more information or volunteer to be a part of this study please call: **Melanie** at: **289-385-6706**

melanie.elliott@brocku.ca

*15-156: The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 2/9/2016 to 2/28/2017.

Appendix L

Example Master Document

R & V – Analysis

R is a 93-year-old man who lives in an apartment in Ontario with his wife of 68 years, V. V is R's sole caregiver. R suffered a stroke in 2008 and during his hospital stay he received an official dementia diagnosis. Two and a half years after the diagnosis doctors found cancer in R's throat and because of this R now uses a speaker (electrolarynx) to help him communicate. Music has always played an integral role in R's life – back to when he was 14 years old and began dancing in the United Kingdom, where he lived at the time. R continued dancing, including when he was deployed in Africa in the army. When R met V they began dancing as a couple and continued to do so in Ontario. They have only recently stopped dancing at the legion, church, and other events but continue to dance in the kitchen. In his later life, R also briefly DJ-ed for certain legion events – the equipment still remains in his bedroom.

Name	R
Gender	M
Year of Birth	1923
Define your Ethnicity	British
Place of Residence	Ontario
How long have you lived here?	24 years
Do you live alone or with others?	With wife
When did you receive the dementia diagnosis?	2008
Are you on any medication related to dementia?	Yes
Do you participate in any alternative therapies?	No

█
P: But in yeah, I was dancing quite a lot,
I've always loved music.

I: Yeah, yeah.

P: Yeah, I still do today I dance all by
myself.

I: I love it, that's awesome.

P: Actually I, he, he was up with me the
other night [Um hmm] and...

I: Dancing?

P: Yeah.

I: Oh, I love it.

R thought I was their daughter when I
arrived "Is that A?".

R's face lit up when I asked him about
dancing and DJ-ing (big smiles and
laughter).



R and V dancing in the kitchen

P: (I/A) and he gets up by himself
sometimes and he just comes you know?

I: He's got some moves?

I: Yeah okay, but you were dancing when
you were 14?

P: Yeah, yeah, no.

I: But not together when you were?

P: No, not together.

I: So, it might have been in your 30s maybe
when you started dancing together?

P: Yeah.

I: Yeah, yeah, yeah. [Yeah] Nice so in terms
of music now are you using it a lot or what
are you, are, you
guys aren't doing the dancing anymore right,
or are you?

She lives "a life of silence".

P: Not...

I: No, no, no and your...

P: I would [Yeah, yeah] but he has forgotten
how.

Talks about him like he's not there even
when he was sitting in front of us – I was
trying my best to directly address him.
She wants to speak for him a lot

I: Yeah, yeah, yeah forgotten the steps yeah
and?

P: He loves the music [Yeah] you know, you
move, you move to, to the music.

I: Right now too specifically right, right
{Laughter}...

P: He's lost it, yeah, yeah.

I: Yeah, not the specific steps but who cares
as long as you still enjoy it right?

Appendix M Similarity and Differences Chart

Similarities	Differences
<ul style="list-style-type: none"> • Males • White • Married • Heterosexual • Dementia diagnosis • Wives as their primary caregivers • Live at home • Music has played a role for most of their lives • Adapted the role of music in their lives to listening • Can recall past memories associated with music • Mention music positively associated with social wellbeing • Lack of self-awareness/willingness to be vulnerable • Role of their partner in the music very much a partnership/connection • Aware of mental health benefits but not physical health • Reached out to their Alzheimer Society at some point during the process post-diagnosis • Use of humor to cope 	<ul style="list-style-type: none"> • Involvement of music – dancing, singing, playing • Ages – 64, 76, 93 • Stage of disease/time since diagnosis – 3, 4, 8 years • Level of acceptance of the dementia identity – Jim is much more accepting of this identity (does talks for the AS) than David who is frustrated with the way the diagnosis was reached and gets uncomfortable talking about the change, and Richard who is so advanced that he doesn't seem to know what dementia is

Appendix N

Example Storyline Analysis Document

Storyline #1: There is value in the use of music for and with individuals with dementia however, this is complicated.

- Opening with information about participants (emphasizing informal use of music at home)
- Overall message of story: There is value in the use of music for persons with dementia but it is complicated.
 - The value lies in:
 - Music positively affecting memory
 - Music bringing the person with dementia to the present moment
 - Connecting to theory or concepts on mindfulness meditation, neuroscience
 - Music provides a point of connection for persons with dementia and their caregivers
 - Music as an expression of embodied selfhood
 - Connecting to theory or concepts on embodied selfhood
 - Music provides a point of connection for persons with dementia and their caregivers
 - Why is this complicated?
 - Music is not going to work for everyone
 - The disease causes changes in the person's relationship to their self
 - The disease causes changes in their relationship to their caregiver
 - The disease causes changes in their relationship to music

Storyline #2: The health and wellbeing of persons with dementia is influenced by music through selfhood, meaning, and relationships.

- Opening with information about participants (emphasizing informal use of music at home)
- Overall message of story: Guided by my theoretical framework – the health and wellbeing of persons with dementia is influenced by music through selfhood, meaning, and relationships.
 - Selfhood
 - Music and selfhood
 - Concept of embodied selfhood
 - Meaning
 - Importance of music
 - Enjoyment of music
 - Role in their life (change over time)
 - Musical memory
 - Relationships
 - To caregivers
 - To others for social wellbeing

Storyline #3: Connection

- Opening with information about participants (emphasizing informal use of music at home)
- Overall message of story: Music acted as a source of connection both in self-connection for the individual with dementia and to their caregiver.
 - Connection to self: through memory, embodied selfhood, clarity of mind/present moment awareness
 - Connection to others: through memory, embodied selfhood, clarity of mind/present moment awareness, working through the changes together

Appendix O

Progression of Disease Diagram

